Working Carers Living Well With Dementia: Sustaining Wellbeing through Work-Life Reconciliation

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Submitted for the award of Doctor of Philosophy

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December 2018

Thesis summary:

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Enabling family carers to live well with dementia is a key UK policy objective. The aim of the Care Act is to sustain the wellbeing of family carers. For those family dementia carers who combine care with a working role, policy incentives are concerned with supporting working carers to sustain the work-life balance. Along with an aging population, the abolition of the default retirement age means that there are likely to be increasing numbers of family dementia carers who face the challenge of sustained care and work. However, very little is known about the experience of working family carers for people with dementia. The aim of this thesis is to improve understanding about the experiences which support and challenge a sustainable work and life balance for dementia working carers. The following questions were addressed to meet the study aims and to develop a working model of sustainability for dementia working carers: Do working and non-working dementia carers differ in caregiving experience, psychological resources, social support, wellbeing, and quality of life? What factors are associated with sustainable psychological wellbeing, everyday functioning and work and life balance among dementia working carers? How do dementia working carers contextualise the experience of sustainable work and life balance?

To address the research objectives, this thesis applied a mixed-methodology using structured interviews and semi-structured interviews, based on conceptual models associated with resilience and role conflict. Secondary structured interview data was firstly explored from a larger national database of 1238 working and non-working dementia carers. Primary structured data was collected from a smaller cohort of 27 dementia working carers. In the larger cohort, structured interviews explored measures associated with psychological resources, the caregiving experience, social support, quality of life, and wellbeing, which were compared between working and non-working groups using multiple regression analyses. In the primary cohort, measures associated with psychological resources, the caregiving experience, work-to-family/family-to-work conflict, coping strategies, care-recipient dependence, everyday functioning (i.e. memory and attention skills), were compared using basic t-tests, between those dementia working carers with low and high wellbeing. Semi-structured, artefact focused interviews were conducted with 24 dementia working carers in the primary cohort. Using 'artefact elicitation', participants were asked to select an object of personal importance which represented the work-life balance. Thematic analyses identified sub-themes which created a richer understanding of the strategies used to sustain work and life, and the challenges facing dementia working carers.

Comparisons between working and non-working dementia carers in the larger cohort, showed that working carers experienced higher self-efficacy, lower perceptions of caregiving competence, and better quality oflife (associated with greater self-esteem and reduced relative stress). In the primary cohort, greater wellbeing outcomes were associated with reduced role captivity, lower caregiving burden, less time-based and strain-based family-to-work conflict, and higher caregiving competence. The main sub-themes from semi-structured interviews demonstrated that dementia working carers managed to achieve sustainability in the following ways: organisational skills; respite strategies; support (home and work); transferable skills (between work and care). The challenges to sustainability for dementia working carers were associated with: caregiving burden; work and life conflict (e.g. time constraints, poor overall wellbeing); outstanding support needs (e.g. respite care, integrated services, emotional, and financial support).

The outcomes of this research suggested that psychological resources, social resources, cognitive resources, a good caregiving experience, and positive coping skills, contribute to sustained work-life

reconciliation for dementia working carers. In conclusion, this thesis demonstrated that dementia working carers utilise a variety of creative methods to sustain work-life balance. The threats to work-life reconciliation discussed however, increase the risk of work and family conflict, and require some rethinking to current policies and practices which are designed to support dementia working carers.

List of Abbreviations

ACS	Attentional Control Scale
APPG	All-party parliamentary group
BPSD	Behavioural and Psychological Symptoms of Dementia
CA	Carer's allowance
CFQ	Cognitive Failures Questionnaire
DfE	Department for Education
DoH	Department of Health
DNWC	Dementia Non-Working Carers
DWC	Dementia Working Carers
DWP	Department for Work and Pensions
EfC	Employers for Carers
ESRC	Economic and Social Research Council
FTD	Frontotemporal dementia
GP	General Practitioner
HMG	Her Majesty's Government
IDEAL	Improving the experience of Dementia and Enhancing Active Life
IRAS	Integrated Research Application System
NIHR	National Institute of Health Research
NHS	National Health Service
ONS	Office for National Statistics
PPI	Patient and Public Involvement
PwD	People/Person with Dementia
QoL	Quality of Life
SAPPR	Self-assessed psychological and personal resources
SCIE	Social Care Institute for Excellence
SF	Short-Form Health Survey
SPM	Stress Process Model
TUC	Trades Union Congress
UK	United Kingdom
WHO	World Health Organization
ZBI	The Short Zarit Burden Interview

Acknowledgments

This IDEAL project-linked PhD studentship was the most challenging project I have ever undertaken. These three years however, have whizzed by and I can hardly believe it is already over. I would like to thank the following people for managing to get me through it, when I often failed to see the light at the end of the tunnel…

Firstly, I would like to thank the funders of this PhD studentship – ESRC (Economic and Social Research Council) for supporting this original project.

Next, I would like to thank the IDEAL Study team - Professor Linda Clare, Dr Anthony Martyr, Dr Sharon Nelis, and Dr Catherine Quinn at The University of Exeter, for my Research associate experience. The support provided by all of my colleagues in the early stages of the IDEAL Study at The University of Bangor, propelled me to apply for the linked studentship for this PhD, and was paramount in enabling me to fulfil my ambitions of completing this PhD.

To my participants - Thank you for sharing so much with me about your often painful and personal experiences. Your personal journeys are so unique and will contribute greatly to the wider knowledge base of dementia working carers in the UK.

I would like to extend a huge thanks to my supervisors – Dr Henglien Lisa Chen and Professor Jennifer Rusted for their tireless dedication, input and faith in this project and me. I would not have been able to see the end (or beginning!) of this thesis without your knowledge, expertise, and patience, of which all were tested on multiple occasions. You installed confidence in me, when I began with very little. I cannot begin to express enough gratitude for the opportunity that taking on this thesis presented for me, and the opportunities it will open as I move onto future endeavours.

Thank you to the following for their assistance with recruitment of my research participants: Sarah Styles; Dr Stephanie Daley; Dr Nicholas Farina; Marcella Carvajal; Yvonne Feeney; Laura Gallaher; Dr. Gosia Razkek.

To the PPI (Patient and Public Involvement) group at Sussex Education Centre), thank you for your recommended enhancements to the study procedure. Your advice was greatly appreciated.

I would also like to thank all the module leaders on the MSc Social Research Methods course. Your support was valuable, and your generous feedback really boosted my self-esteem when it was needed.

Lastly, I'd like to thank my parents. You both have been very supportive and encouraging about my choices in life. I am very lucky to have such a unique and personal relationship with each of you. I am grateful that you are proud of my achievements (even though you still don't know what they mean!).

Without the support of the aforementioned, I would not have seen this thesis through to completion. Thank you all so much again for time, support, and patience.

I look forward to the doors this experience will open in the next chapter of my life.

Table of Contents

Tables, figures, bar charts, histograms, and photos

Chapter 1:

Research background and context

1.1 Introduction

This thesis is primarily concerned with how dementia family carers who remain in employment sustain their wellbeing while managing their work and life. My original concern for the wellbeing of dementia carers arose through my research associate experience in the IDEAL Study[1], where part of this role required me to conduct pilot interviews related to the quality of life (QoL) and wellbeing of people with dementia (PwD) and their carers. This experience enhanced my growing interest in individuals suffering with dementia, but also the challenges of this diagnosis for primary carers. Therefore, I applied for the IDEAL project-linked PhD studentship: Sustaining wellbeing in carers who remain in the workforce, at the University of Sussex in 2015. The research which initially struck my interest when applying for this PhD, was related to previous studies which have found a decline of QoL and wellbeing for dementia carers as dementia symptoms increase in severity (Cassie & Sanders, 2008). QoL remains stable, however, when dementia carers remain in employment, but declines when dementia carers spend more time providing care due to unemployment (Covinsky et al., 2003). My initial interest in this study, therefore, was piqued by the possibility that employment serves as a protective factor for dementia carers.

My personal experience at this point was also poignant in my application for this project. This included not only my academic understanding of the psychological and financial implications of caregiving, but also a personal motivation to learn more about the plights of those carers who provide care for a person with dementia. This curiosity was related to my own experience as the sole support system for parents who are separated

[1]The IDEAL (Improving the experience of Dementia and Enhancing Active Life) Study is funded by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/2 'Improving the experience of dementia and enhancing active life: living well with dementia' (Principle Investigators: L. Clare. Co- Investigators: I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom). The IDEAL Study was a 5-year (2014-18), national longitudinal study with 3 time-points. Further funding has extended the programme to 9 years with 6 time points. The IDEAL Study is examining how social and psychological factors influence the possibility of living well for carers and people living with dementia. See: http://www.idealproject.org.uk/about/

and live alone. In this respect, my intrigue was also coupled with concern for how carers manage to balance their own lives while caring for individuals with often physically and emotionally challenging behaviours. My professional, academic, and personal rationale of the research discussed above, formed the development of my position and role within this study (See Chapter 3.2).

This chapter provides some background for this thesis. It begins with an overview of my initial engagement with the existing understanding of dementia carers, and of those dementia carers who combine care with a working role. It then outlines the arguments to be developed, sets out the aim and objectives of the study, and concludes with an overview of the chapters that will follow.

1.2 Background to the study

The increase in longevity among older populations introduces a corresponding increase in diagnoses of Vascular dementia and Alzheimer's disease (Prince et al., 2013). According to the World Health Organization (WHO, 2017) the number of people living with dementia worldwide is currently estimated at 50 million. It will increase to 82 million by 2030, and triple by 2050. In the United Kingdom (UK), there are around 800,000 people living with dementia (Department of Health (DoH), 2015)). Nearly all of these are cared for by their family, with around 700,000 dementia carers being family carers of a PwD (Lewis et al., 2014). While many male spouses or partners do provide long-term care for PwD, females (e.g. spouses, partners or daughter (-in-law)) predominate in the dementia caring role (Ackers et al., 2009; European Commission, 2012a; Carers Trust, 2014). Many of those are aged 45 to 64 (Carers UK, 2013) which means this caring role could constitute a barrier to their career development and earnings/savings. A report by Carers UK (2011) suggested that around 10% of all carers (for any condition) are from a minority ethnic background. South Asian Indian is the largest minority ethnic group (2.2%), followed by Black Caribbean (0.9%). Furthermore, vascular dementia is more common in minority ethnic groups (particularly South Asian, African and Caribbean) due to a higher prevalence of risk factors such as diabetes, hypertension and cardiovascular disease (Parveen & Oyebode, 2018).

Family caregiving, in general, comprises many instrumental activities of daily living. These include but are not limited to: managing all finances including household bills, housework, shopping and preparing meals (Levine et al., 2003). For dementia

carers, care has been described as more strenuous than caring for individuals with a chronic disease (Brodaty & Donkin, 2009) or physical disability (Ory et al., 1999). This belief is based on the demands of managing the behavioural and psychological symptoms of dementia (BPSD), which affects up to 90 percent of PwD (DoHa, 2009). As the BPSD progress in severity, care usually becomes more strenuous (Health Quality Ontario, 2008), with increasing demands on the carer's time (Cascioli et al., 2008), physical, and emotional resilience. In comparison to family carers of people without dementia, for example, dementia carers have reported providing more help with daily activities, higher levels of caregiving and social activity conflict, more interrupted sleep, as well as feeling more depressed or hopeless (Moon & Dilworth-Anderson, 2015).

The emotional work of dementia family carers is an additional obligation alongside indirect caregiving duties, and often requires continual social interaction (Papastavrou et al., 2007). Bradley et al. (2005, p. 212) referred to this emotional work as the 'labour of emotional maintenance'. Among dementia carers, Simpson and Acton (2013) found that emotional work is based on:

- managing their feelings;
- weighing options about day-to-day activities;
- playing a parental role;
- ensuring the emotional wellbeing of the PwD.

However, this emotional work is often performed with emotional dissonance between the carer's true feelings. Emotional labour for dementia carers, can result in conflicting feelings, where the outcome produced is one of emotional dissonance and/or emotional harmony (Msiska et al., 2014). Research confirms that the emotional aspects of dementia care are the most stressful and can contribute to the breakdown of family care relationships and admittance to care homes (Mioshi et al., 2009; Nelis et al., 2011).

As many dementia carers tend to be older themselves, caring in later life is another risk factor that can diminish QoL (de Oliveira et al., 2015). Impaired physical health among dementia carers is associated with the BPSD, resulting from intensive caregiving tasks, and cohabitating with the PwD (Vitaliano et al., 2003; Pinquart & Sorenson, 2007). Sharing residence with the PwD, for instance, can increase the risk of social isolation (Robison et al., 2009), particularly for family carers of individuals in the later stages of dementia (Zwaanswijk et al., 2013). Witnessing a declining relationship, changes in

physical and cognitive status, and a shift in care demands, can exacerbate psychosocial distress by increasing levels of depression and perceived burden for dementia carers (Oyebode, 2003; Adams et al., 2008; Campbell et al., 2008). Cognitive decline can also occur as a by-product of the chronic stress associated with caregiving (Vitaliano et al., 2005). Moreover, Vitaliano and colleagues (2011) reported that spousal caregivers of PwD may be at a higher risk of cognitive impairment than non-caregiving spouses in response to psychosocial (e.g., depression, loneliness, social isolation sleep deprivation), behavioural (e.g. minimal exercise poor diet), and physiological (e.g., inflammation) mediators. In contrast, other research has demonstrated that the emotional bond in the carer-dyad relationship is an important element of informal dementia care (Norton et al., 2009; Walters et al., 2010; LaFontaine & Oyebode, 2013; Rattinger et al., 2016). Positive experiences of caring for a PwD have been conceptualised as enhanced relationships with others, feelings of self-confidence, and positivity towards life in general (Tarlow et al., 2004). More recently, Cheng and colleagues (2016) found that positive gains among dementia carers were related to embracing the skills acquired through caregiving (i.e. patience, acceptance, purpose obtaining support), retaining a positive mindset, and having a close bond with the PwD.

Besides the additional set of demands of dementia care that stretch family carers' already scarce time and energy, the number of dementia carers who combine care with employment has risen in the UK and other developed countries in recent decades (Molina, 2015). In the UK (i.e. Carers Strategy: DoH, 1998; 2008; 2010) work-family balance is an independent right for those who provide care. For carers, the Carers Strategy is embedded in the government's general principle that paid work is vital for ensuring financial independence, preventing social exclusion, and enriching personal wellbeing. For dementia working carers (DWC), more intense caregiving responsibilities makes combining work and care even more difficult. The public expenditure costs of carers unable to stay in employment have been estimated at £1.3 billion annually (Carers UK, 2015), while employers are losing skilled and experienced staff (Healthways & Coughlin, 2010; NHS (National Health Service) England, 2017)). Furthermore, the number of carers who reduce their participation in the labour market, partially or completely, is expected to rise because of the ageing population and the subsequent increase in the need for carers (Her Majesty's Government (HMG), 2013)). However, people in their fifties and early sixties play a vital role in the provision of unpaid family care in the UK, with relatively low labour market participation rates (Department for Work and Pensions (DWP), 2011)).

Employers thus face the real risk of losing talented people in whom they have invested time and money (Casey, 2011), particularly as the peak age of caring is the same age at which people are likely to have developed the skills employers need (HMG, 2013). Therefore, it is argued that supporting DWC could benefit not only carers themselves, but also their employers and the economy.

The policy on the abolition of the default retirement age of 65 in 2011 (gov.uk, 2011) is one of the factors that will increase the number of DWC in the not-too-distant future. As the period of working life extends, the numbers of DWC who face the challenge of balancing dementia care and working life is also likely to rise. Therefore, as dementia carers are projected to rise in number both nationally and internationally (Carers Trust, 2015), supporting those carers to remain in employment, while protecting their wellbeing, is vital (Organisation for Economic Co-operation and Development (OECD), 2006; Austen & Ong, 2010; Commission on Funding of Care and Support, 2011)).

1.3 Study aims and objectives

The discussion so far has indicated that DWC carry out highly complex and demanding caring roles, while remaining in the labour force at the same time. The number of these DWC is likely to increase in the future. It is to be argued that the contribution of DWC in dementia care is considerable and their wellbeing should be supported. The aim of this thesis, therefore, is to further understand the complexities of balancing work and caring roles, to provide indicators of work-life balance and the threats to work-life balance, and to extend understanding of the factors associated with sustainable wellbeing in family carers of a PwD who are maintaining employment alongside the caring role.

The objectives of the research are as follows:

- To examine the similarity and differences of DWC and dementia non-working carers (DNWC) in QoL, wellbeing, caregiving experience, psychological resources, and social support;
- To define the factors that are associated with sustainable wellbeing, everyday functioning, and work and life balance among DWC;
- To understand the challenges of work and life balance for DWC;
- To discover the way DWC reconcile work and life balance.

1.4 The key focus of the arguments presented in this thesis

To understand more about how DWC are recognised in society, I begin this thesis (see Chapter 2) by exploring the rights of carers generally, and how progress in the implementation of DWC right to work and care in England, is received and situated within a broader agenda of social and employment rights associated with the demographical changes described. Following this, I consider English policies towards work-life balance among older workers' participation in paid work and unpaid caring roles. I then explore the existing literature towards the QoL and wellbeing of DWC, within the last ten years. I then describe the conceptual frameworks in Chapter 3, which are based on the resources working carers utilise to sustain wellbeing and work-life balance, and the factors which challenge wellbeing and work-life balance. In Chapter 3, I describe the IDEAL project-linked, interdisciplinary and mixed-methods design selected for this study, and reflect on my position in the research. I then discuss the research methodology based on the procedures selected for analysis and the ethical principles and considerations.

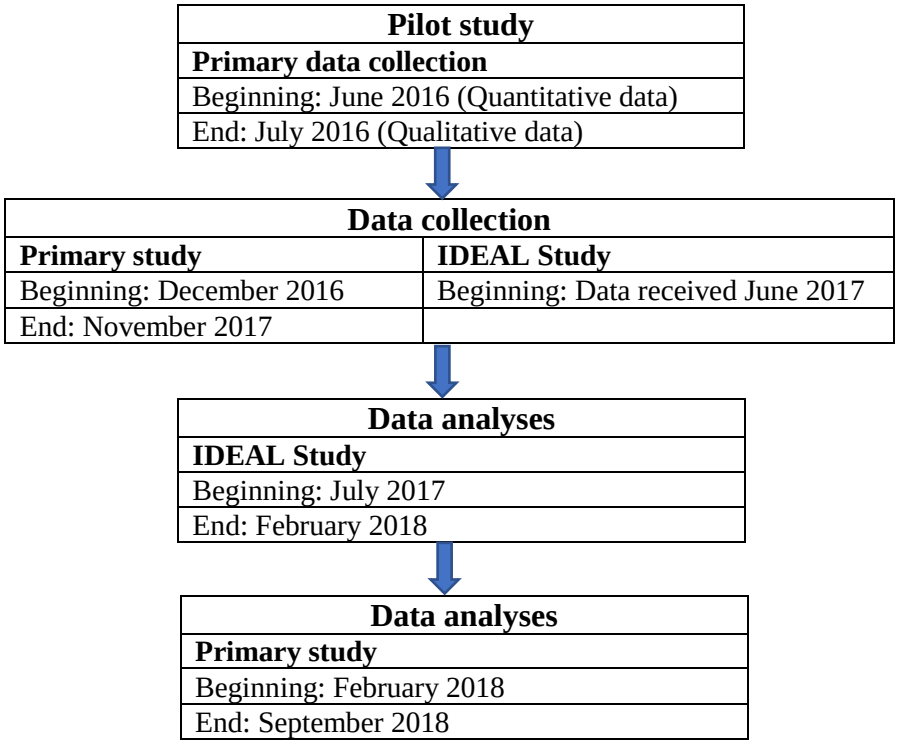
The findings are divided into two parts. I first focus on the national IDEAL cohort data and my primary quantitative data (Chapters 4-6) to generate an overview of the profile of DWC and the factors which contribute~~d~~ to reduced and increased QoL and wellbeing outcomes among DWC. Beginning with Chapter 4, I focus on quantitative analyses associated with QoL, wellbeing, and self-assessed psychological and personal resources (SAPPR) i.e. psychological resources, caregiving experience~~,~~ and social support. This data is extracted from Time 1 of the linked IDEAL Study to provide an overview of the similarity and differences associated with the profile, QoL and wellbeing of DWC and DNWC from a national database.

In Chapter 5, the impact of SAPPR on QoL and wellbeing is explored in further detail, with comparisons made between DWC and DNWC in the IDEAL cohort, to establish whether there are variables unique to DWC, which are associated with QoL and wellbeing outcomes. In Chapter 6, quantitative analyses firstly focus on comparisons between overlapping measures associated with wellbeing between the IDEAL cohort of DWC and DWC in my primary sample. I then explore the relationship between overlapping measures, and measures selected to further explore the work-life balance of DWC in the primary cohort, with wellbeing outcomes.

Furthermore, to gain a deeper understanding of the quantitative findings (Chapter 4- 6), I go on to explore the impact of work-life balance on the wellbeing of DWC based on my

primary in-depth qualitative research: challenges (see Chapter 7) and resolutions (Chapter 8) of sustainable wellbeing and reconciled work-life balance among DWC. The concluding Chapter (9) draws together the relationship between all variables to support the development of a new working model for sustainable wellbeing and work-life balance among DWC. Figure 1.1 provides a visual map showing the timeline for the collection and analyses of both secondary (IDEAL) and primary data.

Figure 1.1 Visual map of secondary and primary data collection and analyses



*Data collection and data analyses for the primary study occurred simultaneously

Chapter 2:

Sustained quality of life and wellbeing of dementia carers in England: A scoping review of policy, practice and research

2.1 Introduction

It is not possible to understand sustained wellbeing through the work-life balance of DWC, without exploring the background of social policy and support. This is because wellbeing concerning DWC could be impacted by the welfare system as a whole. While employment policies apply to DWC only, policies relating to support apply to both DWC and DNWC. The chapter, therefore, consists of an examination of the literature on the policy, support and research relevant to dementia carers that includes DWC and DNWC. The objective of this chapter is to identify the gaps from existing literature to construct the research design of this study on the QoL and wellbeing of DWC. In the UK, many people living with dementia are cared for by their family. In line with the progression of dementia, caring roles can become increasingly challenging and impact the wellbeing of these family carers. For DWC, resources can become even more strained with the challenge of balancing both work and care roles. Progress in the implementation of dementia carer's right to work and care in England is received and situated within a broader agenda of social and employment rights associated with demographical changes.

Therefore, this chapter firstly explored how the increasing numbers of DWC and DNWC have resided within a governance pathway across policy and practice from my scoping research. Secondly, I examine what is currently known about the QoL and wellbeing of DWC and DNWC from my literature review.

2.2 Scoping review of policy

The scoping review was conducted between October 2015 and January 2016, and again, in June 2018. The literature selected for this thesis drew mainly on key texts on policy, dementia care and dementia (working) carer research between 1985 and 2018. Articles relevant to policy response and practice, and QoL and wellbeing of DWC and DNWC, were obtained from: ASSIA: Applied Social Sciences Index and Abstract and IBSS (International Bibliography of the Social Sciences) (1337); Scopus (433); and Web of Science (25). Key search terms included: 'policy', 'policies', 'well-being', 'wellbeing', 'well being', and

'quality of life'. Phrases relating to 'work and life balance' included: 'work life balance'; 'work life conflict; 'work family balance and 'work role conflict'; and the bidirectionality of work life balance: 'life work balance'. To cover all definitions of carers, I inputted the following terms into the databases: carer OR family carer OR informal carer OR caregiver and care*, where the asterisk accounted for any unlikely caregiving terms i.e. caregiving provider. As this study is considering the wellbeing and work-life balance of family carers of a PwD, the terms 'dementia' OR 'Alzheimer's' were included in the literature search.

2.2.1 Rights for dementia working carers and dementia non-working carers: Policy response

This section discusses the response of English social policy to carer's social and employment rights relevant to DWC and/or DNWC. Several European states have mixed rights pertaining to social care and employment in their legal frameworks for carers (Pfau-Effinger et al., 2009). Nonetheless, England is one of the countries which has the longest tradition in acknowledging the carers' rights to care and work. For example, informal carers in the UK were granted statutory eligibility for an assessment of their own needs and of their ability to provide care under the Carers (Recognition and Services) Act 1995 (Gillies, 2000). The Carers (Equal Opportunities) Act 2004 placed a legal duty on local authorities to provide a carer's assessment which is a separate needs assessment for carers in their own right. It aims to assess carers' welfare, wellbeing, and employment status, as well as assess the outcomes that carers wish to achieve in their day-to-day life, and whether the proposed provision of support could fulfil those outcomes (Glendinning et al., 2015). In implementing the Care Act provisions for an adult carer's assessment, local authorities are also required to consider the carer's wishes in respect to education and employment (HMG, 2014). These rights exist even if the care recipient refuses or is ineligible for local authority support (Glendinning et al., 2015). Furthermore, since 2008, carers are entitled to a personal budget or a cash direct payment to use in ways that suit their individual needs (DoH, 2008; DoH, 2010; HMG, 2010).

Governments have also put measures in place to reconcile employment and caring, where one of the main costs of caring is reduced labour market participation and the associated long-term consequences for pensions (European Commission, 2016). Work-family reconciliation is recognised as an independent right in the European Charter of Fundamental Rights (Caracciolo di Torella & Masselot, 2010), although this is mainly

focused on the workplace rights of parents with young children. The aims of UK work-life legislation have been developed to promote and establish a healthy work-life balance and to remain alert to societal changes, such as the aging population (Trades Union Congress (TUC), 2010)). In 1999, the launch of the National Strategy for Carers (HMG, 1999) drew attention to the challenges facing carers in balancing paid work with caregiving. It emphasised the need to keep carers engaged with the labour market to stave off potential poverty and social exclusion. In 2009, the National Dementia Strategy (gov.uk, 2009) placed priority on improving the quality of support for dementia carers. Besides aiming to provide good quality information, this strategy focused on ensuring that dementia family carers gain access to an assessment of their own needs, and to supportive structures, as well as determining their outstanding support needs.

In 2012, the British Prime Minister set a challenge to deliver major improvements in dementia care and research by 2015, including improvements in health and social care, creating dementia friendly communities, and improving dementia research (DoH, 2012). The Carers Strategy for 2014 to 2016 aimed to improve identification and involvement of carers by healthcare professionals, so that they can access the information, advice and support that is specific to their needs (HMG, 2014). In its Commitment to Carers, NHS England (2014) emphasised that primary healthcare for carers will include an offer of a health check and signposting to relevant services. The Carers Strategy further promised that the Government would disseminate learning from the programme to support the NHS in delivering its plans to improve identification and recognition of carers who are of working age.

At a national level, recent concerns about how best to support working family carers have been featured on the political agenda for several European countries (European Commission, 2016). When dementia strategies have been compared across European states (Skladzien et al., 2011), financial remuneration for providing informal caregiving support has been the most important support for informal carers, followed by flexible working arrangements and pension protection (European Commission, 2012b). Respite care services are also the most common type of services employed across England and several European countries (Courtin et al., 2014). For working carers in England, support with work-care balance includes the backdrop of flexible working laws, which are derived from European Union (EU) Directives such as the Employment Rights Act 1996, Employment Relations Act 1999 (Smith & Baker, 2013), and the Employment Act 2002. These labour laws include flexible working patterns, care leave, and emergency leave. Carers' Strategies in 1999, 2008,

and 2010 (HMG, 1999; HMG, 2008; HMG, 2010) have emphasised the role of employers in providing flexible working, as part of the work-life balance agenda via the Work & Families Act 2006.

The most controversial social policy in supporting work and care rights of dementia carers in the last few decades, is the Care Act 2014. The Care Act integrates and improves previous legislations by "putting carers on an equal legal footing to those they care for and putting their needs at the centre of the legislation" (The Care Bill explained, 2013, p.10). It seeks to strengthen the recognition and rights of family carers and receivers of care, defining the importance of wellbeing, and carers' rights in relation to social care (Larkin & Mitchell, 2016). Under the current Care Act, wellbeing has been conceptualised as a broad concept and a subjective judgement of the following:

- personal dignity (including treatment of the individual with respect);
- physical and mental health and emotional wellbeing;
- protection from abuse and neglect;
- control by the individual over day-to-day life (including over care and support provided and the way it is provided);
- participation in work, education, training or recreation;
- social and economic wellbeing;
- domestic, family and personal;
- suitability of living accommodation;
- the individual's contribution to society.

As part of carers' rights to a healthy work-life balance, then, the Care Act has recognised that aside from acting in the capacity of carer, working carers also require support of their own. However, while Carers Allowance (CA[2]) supports little or no income from paid work (e.g. low paid or part-time work) (Fry et al 2011; Glendinning et al., 2015), the restrictions associated with CA can limit the choices and autonomy of work-life balance for DWC. Nonetheless, overall, English policy has secured significant social and employment rights to support DWC and DNWC. However, as working carers prepare for a longer working life, juggling the demands of dementia care with employment is likely to become a

[2]Carer's Allowance (CA) is provided to carers who care for 35 or more hours each week and are aged 16 and above. To qualify for CA, working carers' personal weekly earnings must be under £110.

growing concern for carers, employers, and policy makers. Therefore, while highlighting the response of policy to the rights of DWC and DNWC, it is also important to have an overview of how policies have been implemented in practice for DWC and DNWC.

2.2.2 Support for dementia working carers and dementia non-working carers: Practice

It is important to note that most of the literature reviewed includes carers as a homogeneous group. This means that little is known about how precisely the above policies are received in practice by DWC and/or DNWC. Nonetheless, research referred to in this section provides a broad understanding of how current policy is received by DWC and DNWC.

According to Twigg (1989), to sustain the caring role, firstly, family carers need to receive help as a by-product of the services aimed at the care recipient. Pickard and colleagues (2018) further found that when the cared-for person for did not receive at least one key service' (e.g. home care, personal assistant, day care, meals, short-term breaks), the carer was subsequently more likely to leave employment because of caring. This suggests that the absence of services can contribute to the carer leaving work. Secondly, carers need to receive specific support for themselves. In England, such efforts have been made by local authorities and non-governmental organisations. Four charities have clear evidence of how they support dementia carers. The Alzheimer's Society (2017a) for instance, has stated that most (96%) of their dementia carer recipients valued their services of advocacy, befriending, community support, day care, dementia support, and home care services. Nonetheless, the Dementia Friendly programme of Age UK (2015) prioritised their local branches to support the QoL of carers for people with *early* stage dementia. Carers Trust (2015) and Carers UK (2015a), meanwhile, are educating carers on how to sustain their physical and mental wellbeing, and the access of relevant support. Working carers are also informed of their employment rights, including the receipt of CA, flexible working rights, and obtaining an assessment of their needs.

However, recent systematic reviews (e.g. Khanassov & Vedel, 2016; McCabe et al., 2016) found service supports are not yet sufficiently meeting the needs of dementia carers. Specific service support in promoting dementia carers' psychological wellbeing (e.g. managing depression or burden) was also mixed (Dickinson et al., 2016). When essential components of support (i.e. long-term interventions, individualised education, specialised needs-based support, multi-disciplinary teams, and ongoing follow ups) with dementia

carers have been delivered, they have shown a positive impact on reducing caregiver burden and improving QoL (Goeman et al., 2016). However, many dementia carers who provide care for 10 or more hours a week have perceived an unmet need for services (Brimblecombe et al., 2017). Brimblecombe and colleagues further identified that unmet needs were associated with the disability of the care-recipient and the carer's relationship with the care-recipient. Adult children for example, perceive a higher unmet need for services.

In 2014, the launch of a two-year project with local authorities was announced, aiming to find out more about how adult carers can be supported to remain in paid employment (All-party parliamentary group (APPG), 2015)). Following this project, the APPG advised that every workplace should have a formal or informal carers policy, detailing organisational support for those with caring responsibilities. Wider recommendations were based on: making CA available for those who are studying, thereby increasing the opportunities for up-skilling, retraining, and career progression; introducing a form of statutory care leave for family carers of the "sandwich generation" (i.e. those with young children and elderly dependents); government and employers supporting greater recognition of the skills developed whilst carrying out caring responsibilities; a greater policy focus on providing effective employment support for those considering a return to work following care leave (APPG, 2016).

Evidence over how local authorities support dementia carers, however, is mixed. Research (Mitchell et al., 2013; Glendinning et al., 2015) shows that while dementia carers played important roles in PwD assessments and support planning, they were less likely to receive carer's assessments or support of their own. When carers did receive carer's assessments, they were perceived as 'one-off' events, which were neither recent nor regularly reviewed. Disconcertingly, support options were directed towards the caring role, as opposed to wider aspirations relating to employment, learning and leisure, as required by the Care Act. In line with these findings, Carers UK (2017) reported that while over half (65%) of 7,000 family carers researched received a carer's assessment, only 32% of those felt that their need to have regular breaks from caring was thoroughly considered, and fewer than half (45%) reported that their ability and willingness to provide care was accounted for and reflected in the support they received. Only a third (34%) felt that the support needed to look after their own mental and physical health was thoroughly reflected in the assessment process.

Regarding individual budgets for carers, Jones and colleagues' (2014) pilot study indicated that individual budgets could help to keep carers mentally and physically well and

could support carers in achieving a state of independence outside of the caring role. However, Larkin and Mitchell (2016) found that there is relatively little policy action towards personalisation, choice and control for family carers. Such inaction appears inconsistent with English public recognition and initiatives on the rights of carers (HMG, 2008). This has, in part, been attributed to the problematic nature of separate user and carer legislation (Mitchell et al., 2014). Other contributory factors include an unclear carer-dyad relationship due to the interdependent and reciprocal nature of caregiving relationships (Fine & Glendinning, 2005; Larkin & Milne, 2014). Furthermore, Pickard and colleagues (2016) added that family carers (inc. DWC and DNWC) who do not provide full-time care (i.e. DWC) could also fail to reach the attention of their local authority.

The concern of carer's assessments in practice was raised by several scholars. Mitchell et al. (2013) and Glendinning et al. (2015) found that many practitioners were unclear about how to carry out the carer's assessment. As a result, there was an absence of clearly articulated goals and service delivery (Bunn et al., 2016). Seddon and Robinson (2015) further found that practitioners were hesitant to assess carer needs via a separate assessment process, since much needed supportive structures remain unaddressed by traditional services. They argued that the reliance on structured, problem-focused protocols fail to capture the motivations for caring and the multifaceted lives of carers, where current assessment practice presumes that one individual is responsible for caring. Such assumptions bypass the contribution of support networks, the inter-relationships among those involved, and their own support needs. The reciprocal nature of caring relationships is also overlooked, where a one-way direction of care is assumed. This can be especially problematic for spousal carers, where mutual support, and a complex interplay of emotions and changing responsibilities is an extension of a pre-existing relationship. Taking a longitudinal perspective, Lloyd (2000) stressed that when practitioners presume a one-way direction of care, they are missing the complex judgements that define caregiving. This argument is further supported by Glendinning and colleagues (2015) who found service users' personal budget allowance is reduced to take account of the support provided by family carers. Despite carers having social and employment rights then, evidence suggests that current practice continues to regard carers primarily as a resource or a co-worker, rather than a co-client (Twigg, 1989; Courtin et al., 2014).

The one-way direction of care and inconsistent support services for carers is particularly concerning for working carers. Emotional and practical support, for instance, are linked to increased morale, enabling carers to cope better by reducing feelings of isolation

for carers who want to return to or remain in the workforce (Social Care Institute for Excellence (SCIE), 2018)). However, Milne and colleagues (2013) identified that accessing information and advice, affordable good-quality social-care services, a joined- up needs assessment of the carer-dyad, and the identification of carers in the workforce by employers, were pivotal yet unacknowledged issues. Earlier research has similarly found that the unsatisfactory skills of formal support services impact on working carers, who need good quality and reliable services to be able to balance work and care (Arksey et al., 2005; Yeandle et al., 2007; Arksey & Glendinning, 2008). Services that are perceived as inflexible, unreliable or of poor quality, can discourage carers from working and caring (Phillips et al., 2002; Pickard 2004).

Among working carers, Yeandle & Buckner (2017) found that positive improvements to workplace flexibility options and modest employment protection and rights could increase the likelihood of carers remaining in paid work. However, by 2011, the support, services and rights available to working carers remained minimal. Research by Carers UK (2017) also found a high number (73%) of working carers researched were not being given sufficient assessment and support by local authorities to combine work and care. Further evidence has found that the impact of working while caring for someone with dementia includes a 'disconnect' between employers' policies and employee experience (Employers for Carers (EfC), 2011)), where only 48% of 982 carers interviewed were offered flexible working arrangements. Moreover, while 33% of employers had a specific policy for carers, this was recognised by only 19% of employees. These findings suggest that in the workplace and social care practice, care and employment support is not always translated into practice for working carers. This could suggest that the failures of some workplaces to enact implementation of policies for working carers, are also indicative that current government policies hold little weight in terms of clarity and enforcement in many organisations. Therefore, the need for services and support for those working carers (inc. DWC) remains high (Ismail et al., 2014; Maplethorpe et al., 2015; Burchardt et al., 2016).

Arguably, more research on DWC is required to support practitioners in gaining better understanding of the difficulties of work-life balance, and the outstanding support needs of DWC. Following the Carers Strategy, a rapid increase of ongoing dementia research in the UK is being undertaken to explore the wellbeing of dementia family carers. For example, work funded by the Alzheimer's Society is exploring how to reduce stress and improve the QoL and wellbeing of family carers (Alzheimer's Society, 2016; 2017b; 2018). Research funded through the ESRC and the National Institute of Health Research (NIHR),

meanwhile, is exploring the social and psychological factors responsible for influencing the possibility of living well for PwD and their family carers (e.g. Clare et al., 2014), and the development of current services to help PwD, dementia carers, and healthcare workers (Page et al., 2017a). However, none of those focus on DWC.

2.2.3 Wellbeing and work-life reconciliation

Reconciliation is a sociological concept that has been used to express the balance between working life and family life. It is closely linked to how the role and position of the individual is viewed in the family, and in society (Caracciolo di Torella & Masselot, 2010). The reconciliation of work and personal life has been a European policy agenda since the 1970's (Crompton & Lyonette, 2006), and began with women entering the workforce. The Sex Discrimination Act 1975, together with the Race Relations Act 1976 and the Equal Pay Act 1970, supported work–life balance issues by insisting that employers consider gender equality (Labour Research Department (LRD), 2001)). The notion of working times also entered labour relation discussions during the 1970s and 1980s, when the rise of employment could no longer be guaranteed (Meiskins, 1998; Arthur, 2002). The demands of employment are composed of the physical, psychological, social and demanding aspects of the job that require sustained psychological (cognitive or emotional) concentration (Schaufeli & Bakker, 2004). For working carers, however, more intense caregiving makes balancing work and care more difficult (DWP, 2014). Work- family conflict has been described as a struggle to balance work and family, where work may interfere with family time and vice versa (Greenhaus & Beutell, 1985). There have been many detrimental effects of work-family conflict reported among carers of elderly dependants. These have been identified by research and include but are not limited to job dissatisfaction, turnover, and areas of wellbeing, including reduced depression, life and marital dissatisfaction (Gignac et al., 1996; Allen et al., 2000; Michel et al., 2009). For family carers of elderly dependants, the negative effects of caring on work performance are also apparent and include: lateness; absenteeism; increased sick leave; loss of energy and a greater likelihood of making mistakes at work (Phillips, 1995; cited in Hoff et al., 2014; Gignac et al., 1996). Family-work conflict has also been associated with reduced job and life satisfaction, and depression (Cunningham & De La Rosa, 2008; Neal & Hammer, 2009; Bagger & Li, 2012). Family-work conflict is "a form of inter-role conflict in which the general demands of, time devoted to, and strain created by the family interfere with performing work-related responsibilities" (Netemeyer et al., 1996, p.401). The extent to which family interferes with work is dependent on care demands that

have been determined by the care recipient's needs. Jones and Fletcher (1996, p. 34) define these demands as "the degree to which the environment contains stimuli that peremptorily require attention and response". Demands are the ''things that have to be done'' and are measured by the amount of care required and the time invested in caring responsibilities. The effects of work-family, and family-work conflict have been found to be higher among women than men (Gignac et al., 1996), where it has been hypothesised that women are more likely to report more family-work conflict at least, because women often have prime responsibility for managing home-related crises (Wood & Eagly, 2002).

King et al. (2014) highlighted that the time spent on caring is a threat to work-life reconciliation, where the employment of approximately 790,000 working carers aged 16- 64 was at risk because care conflicted with the working role. Employed men and women in their fifties who started providing weekly care for 10 or more hours, were particularly affected by conflicting demands and were less likely to remain in employment. Doweick & Southern (2014) reported that in the UK alone, intensive caregiving responsibilities have led to 66,000 carers cutting their working hours to make time for caring, and 50,000 carers who have left work altogether. Likewise, Carers UK (2017) found that the impact of juggling work and care among 2,500 working carers meant that 43% had given up work completely, 21% reduced their working hours to provide care, and 13% retired early to provide care. For working carers who did remain in employment, nearly half (46%) said that their job was negatively affected by caring through tiredness, lateness and stress, while 14% of carers took a less qualified job or turned down a promotion to fit around their caring responsibilities. Many working carers (72%) were also more likely to have suffered with lowered wellbeing because of caring, including poor mental health (i.e. stress and anxiety), with 55% of working carers stating that their physical health had worsened because of caring. Two thirds of working carers (67%) also said they had experienced poor sleeping patterns, and around half said they had reduced physical exercise and found it difficult to maintain a balanced diet. A quarter of working carers also reported that their General Practitioner (GP) did not know that they were carers.

Many people with caring responsibilities, however, can and do balance work and care, where it has been recognised that most carers of working age wish to stay in touch with the labour market. In comparison to non-working family carers for instance, employment has been found to serve as a respite from the responsibilities of care, protecting against the detrimental effects of caregiving stress (Healthways & Coughlin, 2010). In addition to securing financial independence, work is also perceived as enhancing the carers' own lives

and the lives of those of those they provide care to (Utz et al., 2011; DWP, 2014). Employment can prevent social exclusion, and enrich personal wellbeing (Hillage & Pollard, 1998), by increasing personal satisfaction from work-based achievements and increasing the likelihood for greater social integration and partaking in activities of interest (Utz et al., 2011). Söderhamn et al. (2013) similarly found that among Norwegian employed dementia carers, employment provided a feeling of enthusiasm, freedom and a good conscience, when respite support was in place.

Research (e.g. Hoff et al., 2014; Principi et al., 2014) that has examined the work restrictions of midlife working carers of older people in Germany, Greece, Italy, Poland, Sweden, and the UK has found that more restrictions have been reported in the UK, Germany and Greece, particularly by women. In all countries, a high number of care hours, high care recipient dependency, a reduction in working hours and an absence of supporting networks were common among carers. For most carers, a trusting, professional relationship with line managers was essential (Hoff et al., 2014). In terms of career development, however, cohabiting with the care-recipient was associated with fewer difficulties for family carers in the UK. This was related to the greater difficulty in managing distance caregiving without a reliable support network. In the UK, working family carers were also more likely to be working in the public sector, which was attributed to the increased likelihood of securing shorter-term contracts and greater opportunities for care leave. Pressure was alleviated when companies supported internal transfer to a position that provided more flexibility (Hoff et al., 2014). As with previous research (Utz et al., 2011), carers also emphasised the importance of continuing to have an identity as employees rather than just caregivers (Hoff et al., 2014).

However, while research on the wellbeing and work-life balance of working carers of older dependents has been more extensive, the presentation of a dementia diagnosis itself creates very different challenges (DoHa, 2009)~~,~~ which cannot easily be applied to working carers of elderly care recipients. In current research literature, there is a knowledge gap in studies that have explored the work-life reconciliation of DWC in the UK. Therefore, opportunities to better support DWC are being missed. While research with DWC is limited, research with DNWC provides a platform on which further developments can be made to assess DWC wellbeing.

2.3 Empirical research on the wellbeing and work-life reconciliation of dementia carers: Literature review

The literature review was conducted between October 2015 and January 2016, and again, in June 2018. The literature selected for this thesis drew mainly on key texts on wellbeing, QoL and work-life balance in dementia care and dementia (working) carer research between 1985 and 2018. Key search terms included: 'well-being', 'wellbeing', 'well being', and 'quality of life'. Phrases relating to 'work and life balance' included: 'work life balance'; 'work life conflict; 'work family balance and 'work role conflict'; and the bidirectionality of work life balance: 'life work balance'. To cover all definitions of carers, I inputted the following terms into the databases: carer OR family carer OR informal carer OR caregiver and care*. As with the scoping review, the terms 'dementia' OR 'Alzheimer's' were included in the literature search. Articles related to QoL and wellbeing were selected on the basis that they included: a) DWC or DNWC; and b) measured QoL, wellbeing, and health outcomes generally. Although the Care Act concentrates on the wellbeing of carers, both QoL and wellbeing were selected for this literature review because indices of QoL and wellbeing (i.e. self-esteem, self-efficacy etc.) are frequently interchangeable in both outcomes (Camfield & Skevington, 2008; Bosboom et al., 2009; Diener & Chan, 2011; Tyack & Camic, 2017; Skevington & Böhnke, 2018). This meant that there was a greater likelihood of locating studies with DWC than if wellbeing outcomes alone were explored. Articles centred on QoL and wellbeing were excluded on the basis that they were: a) over ten years old (i.e. 2007 and earlier) due to developments in wellbeing assessments (Keyes et al., 2002); b) focused exclusively on outcomes of an intervention or randomised control trial; c) focused on dementia carers providing end of life support; d) focused on DWC and/or DNWC who care for PwD in care homes.

A total of 50 studies were applicable to the QoL and/or wellbeing of DWC and/or DNWC. Across studies relating to DWC and DNWC (excluding 5 systematic reviews, 4 literature reviews, and 1 realist review), data was collected from a total of 1109 DWC and 11,691 DNWC, who were mostly female, and comprised spouses, daughters/daughters- in-law, sons/sons-in-law, adult children/parents and others (nephew, niece, siblings and friends). Only three out of 40 empirical research were conducted in the UK. Other studies were conducted in: Norway; Germany ; Sweden; Canada; Asia; USA ; Turkey ; Switzerland; Finland; France; Cyprus; Europe wide; and Australia. There were 21 out of 40 empirical research which included participants who were DWC and only one of those

were from the UK (i.e. McCabe et al., 2018). However, the majority of this research (37 out of 40 studies) did not intentionally explore the experiences of DWC (excluding Wang et al., 2011; Wang et al., 2013; Alpass et al., 2017), while other studies (inc. McCabe et al., 2018) failed to account for the number of DWC in their sample (i.e. Kjällman-Alm et al., 2013; de Oliveira & Hlebec, 2016; Johannessen et al., 2016; O'Rourke et al., 2016; McCabe et al., 2018). This represents a considerable knowledge gap in the QoL and wellbeing of DWC in England and elsewhere. Most of the studies (28 out of 40) employed quantitative analyses. Some (10 out of 40) employed qualitative techniques i.e. interviews/open-ended questionnaire responses; focus; or a combination of interviews and focus groups. Other studies (2 out of 40) utilised mixed-methods, consisting of both quantitative and qualitative data collection. It indicated the general and, particularly, the in-depth research in QoL and wellbeing of DWC and DNWC is scattered to support policy makers and practitioners in assisting dementia carers. Within those ten non-empirical studies, there were five systematic reviews; four literature reviews; and one realist review. Overall, despite the significant contribution of family carers in dementia care, there is insufficient research and understanding of their QoL and wellbeing to sustain their ability to care for themselves and PwD. Nonetheless, some important lessons could be learnt from the literature reviewed.

2.3.1 Factors that impact quality of life and wellbeing of dementia non-working carers and dementia working carers

As outlined in Table 2.1, 21 studies referred to the wellbeing of dementia carers, 14 studies referred to the QoL of dementia carers, 6 studies referred to both outcomes, and 9 studies referred to neither, and instead focused on indices associated with both QoL and wellbeing. Nineteen authors explored the impact of demographic factors (i.e. gender, age, the caregiving relationship) on indices of QoL and wellbeing (i.e. psychological variables, physical health), as well as mediators of caregiving strain (i.e. social support, coping strategies). In this section, I identify the emergent factors which could impact on the outcome of wellbeing and/or QoL of dementia carers. The factors include demographic characteristics of dementia carers, the health condition of PwD and the carer-dyad relationship, which are inter-linked. It is important to note that in the 40 empirical studies reviewed, employment status was not specified for all dementia carers – only 21 out of 40 research included DWC and among these studies, five did not specify the employment status of participants – so the

employment status of the carers in these studies cannot be confirmed.

Table 2.1: Demographic, psychological, physical, and social resources associated with quality of life and wellbeing among dementia working carers and dementia non-working carers

Author	BPSD	Demographic (i.e. age, gender, carer-dyad relationship) factors	QoL/ Wellbeing (WB)	Psychological variables	Physical health	Social support	Coping strategies
Cheng et al. (2013)*	X		WB	X		X	X
Cox (2013); Häusler et al. (2016)		Carer-dyad relationship	WB; QoL	X			X
Crellin et al. (2014); Alves et al. (2017); Ali & Bokharey (2015)			QoL; QoL; N/A	X	X		X
Akpınar et al. (2011)*		Gender	N/A	X			
Bruvik et al. (2012)*; Alpass et al. (2017)*; Cunningham et al. (2018)			QoL; QoL; WB	X			
Anderson & White (2018)*		Carer-dyad relationship	N/A	X	X	X	X
Braun et al. (2009)	X	Gender; Carer-dyad relationship	WB	X	X	X	
Braun et al. (2010); O'Rourke et al. (2011)*; Chappell et al. (2015)		Carer-dyad relationship	WB; Both; WB	X			
Bristow et al. (2008)*; de Oliveira & Hlebec (2016)*; Tay et al. (2016)			WB; Both; Both	X		X	
Davies et al. (2012); Janssen et al. (2017)*	X	Carer-dyad relationship	WB; QoL	X			
Fonareva & Oken (2014); de Oliveira et al. (2015); Farina et al. (2017)			Both; QoL; Both	X	X		
Stiadle et al. (2013); Ervin et al. (2015); Fauth et al. (2015); Cheng (2017)*	X		WB; WB; WB; N/A	X			
Fauth et al. (2012)		Carer-dyad relationship	WB	X	X		
Johannessen et al. (2016)*			WB			X	X
Kaufman et al. (2010)*		Gender	Both	X		X	
Kjällman-Alm et al. (2013)*; McCabe et al. (2018)*			N/A; N/A			X	

Välimäki et al. (2009)*; Nicolaou et al. (2010).	X	Gender	Both; WB	X			
Pattanayak et al. (2011); Nurfatihah et al. (2013)*; Alvira et al. (2015); Kimura et al. (2015)*			QoL; QoL; Both; Both	X	X	X	
Wang et al. (2013)*; Parkinson et al. (2017)			WB; QoL	X	X	X	X
Rehman et al. (2009); McLennon et al. (2011); Papastavrou et al. (2011); Snyder et al. (2015)			WB; N/A; WB; WB	X			X
Rosness et al. (2011)*		Older age; Carer-dyad relationship; Additional caregiving responsibilities i.e. offspring	QoL	X			
Quinn et al. (2015)		Carer-dyad relationship	WB				X
Raivio et al. (2015)	X	Carer-dyad relationship	WB	X		X	
Wang et al. (2011)*			WB	X			
Wawrziczny et al. (2017)*	X	Carer-dyad relationship	N/A	X	X	X	
Yang et al. (2014)	X	Carer-dyad relationship	N/A	X			X

*Research including DWC

N/A – Not applicable

2.3.2 Demographic factors Dementia non-working carers

Several studies found that the demographic characteristics of dementia family carers were particularly important in determining QoL and wellbeing outcomes. A total of five studies found that that gender was a mitigating factor in outcomes, where female carers reported a higher level of carer burden than male carers, in areas associated with: PwD dependence, depression, as well as physical and social burdens (Braun et al., 2009; Välimäki et al., 2009; Nicolaou et al., 2010; Akpınar et al., 2011; Wawrziczny et al., 2017). Nonetheless, there is variation within female dementia carers. When type of carer-dyad relationship was explored for instance, wives experienced poorer self-esteem and higher caregiving burden than daughter carers (Chappell et al., 2015). Rosness and colleagues (2011) confirmed that being married to the PwD and having additional caregiving responsibilities (i.e. offspring) were factors that contributed to a reduced QoL. In two studies, older age was associated with reduced QoL, increased depression and more caregiving strain (Rosness et al., 2011; de Oliveira et al., 2015). Being a younger carer was associated with reduced QoL, but only when high caregiving stain was apparent (Janssen et al., 2017).

2.3.3 Health condition of people with dementia - Dementia non-working carers

Many studies (13 out of 40) focused on caregiving stressors associated with BPSD, finding an effect on caregiving burden, physical health, depression, and emotional strain (Braun et al., 2009; Nicolaou et al., 2010; Davies et al., 2012; Stiadle et al., 2013; Ervin et al., 2015; Fauth et al., 2015; Raivio et al., 2015; Cheng, 2017; Janssen et al., 2017; Wawrziczny et al., 2017; Anderson & White, 2018). More severe dementia symptoms were associated with poorer wellbeing and were particularly pronounced when care-recipients had fronto-temporal dementia (FTD) (Nicolaou et al., 2010; Cheng, 2017).

2.3.4 Carer-dyad relationship - Dementia non-working carers

Many studies (13 out of 40) identified the impact of the carer-dyad relationship on QoL and wellbeing (Braun et al., 2009; Braun et al., 2010; O'Rourke et al., 2011; Rosness et al., 2011; Davies et al., 2012; Fauth et al., 2012; Cox, 2013; Stiadle et al.,

2013; Yang et al., 2014; Chappell et al., 2015; Raivio et al., 2015; Wawrziczny et al., 2017; Anderson & White, 2018). Dyadic relational resources associated with mutuality and preparedness for caregiving moderated the effects of role strain (Yang et al., 2014), while the long-term effect of closeness in the relationship predicted poorer mental health. Reduced closeness, however, predicted poorer physical health but greater mental health in the long-term (Fauth et al., 2012). The positive impact of the carer-dyad relationship was observed in two other studies, which found that a close carer-dyad relationship provided a sense of reward and accomplishment, and enhanced positive coping strategies (i.e. creativity, assertiveness, advocacy) (Anderson & White, 2018), and improved carer's wellbeing (Braun et al., 2010; O'Rourke et al., 2011; Stiadle et al., 2013). Factors associated with the caregiving experience (i.e. positive aspects of caring, a positive carer-dyad relationship, feelings of accomplishment, and meaning of caregiving role), were also related to how dementia carers sustain the caregiving role (Hwang et al., 2017).

The above studies highlight the significance of demographic factors (i.e. gender; age; care-recipient behavioural status; the carer-dyad relationship), in sustaining or challenging the QoL and wellbeing of dementia carers. Spousal carers caring for spouses/partners with severe dementia and with a poorer carer-dyad relationship, appeared most vulnerable to the detrimental effects of caregiving strain.

2.3.5 Indices associated with quality of life and wellbeing - Dementia non-working carers

Several studies explored the more complex relationship between indices of QoL and wellbeing outcomes. Psychological indices such as higher self-efficacy for example, were associated with higher QoL (Crellin et al., 2014; Tay et al., 2016), and higher self-efficacy was effective for controlling upsetting thoughts, and obtaining respite (Cheng et al., 2013). These findings demonstrated the correlation of higher self-efficacy with reduced caregiving burden in response to disruptive behaviours in the PwD, and lower depression.

Multiple biopsychosocial indices associated with social and psychological resources, good physical health, and safeguarding QoL, were hypothesised to reinforce carer resilience (Parkinson et al., 2017), while personality type, self-efficacy, feelings of mastery, and positive responses to stress, are all important for determining carer vulnerability and QoL (Cox, 2013). Poor physical and cognitive health meanwhile, have

been found to predict poor QoL and wellbeing (Bruvik et al., 2012; Fonareva & Oken, 2014). In another study (Alvira et al., 2015), poor self-esteem and lack of family support correlated with caregiver burden and psychological wellbeing, while a disrupted schedule (i.e. interference in daily life) and caregiver burden, were also relevant to psychological QoL and wellbeing outcomes. Physical health problems were clearly associated with caregiver burden, psychological wellbeing and QoL. Other studies have confirmed that improved QoL outcomes are associated with carers having better physical and mental health, greater independence, and partaking in more respite activities (Farina et al., 2017). Enhanced carer wellbeing was similarly associated with reduced negative emotions such as stress, burden, and depression (Cunningham et al., 2018).

These studies suggest that there is a complex interrelationship between indices of QoL and wellbeing, which relate to psychological, physical, and social resources. Positive experiences of caregiving, family support, an uninterrupted schedule and greater self-efficacy were also significant to dementia carers' ability to sustain the caregiving role.

2.3.6 Impact of coping strategies - Dementia non-working carers

Few studies (6 out of 40) highlighted the significance of instrumental and emotional social support for sustaining QoL and wellbeing among dementia carers (Bristow et al., 2008; Alvira et al., 2015; Raivio et al., 2015), including satisfaction with professional services (Raivio et al., 2015). Difficulties in accessing formal long-term care, however, resulted in a lower satisfaction with life, while the opposite is true for carers with larger social networks and an active participation in physical and social activities (de Oliveira & Hlebec, 2016). Use of social support as a coping mechanism is also positively correlated with physical and psychological QoL domains (Pattanayak et al., 2011). Females were found to have greater social support than males, which was linked to a greater satisfaction with life (Kaufman et al., 2010).

Ten studies also explored the association of active (i.e. problem-focused) coping strategies (Tay et al., 2016; Hwang et al., 2017) and resilience (Rehman et al., 2009; Papastavrou et al., 2011; Pattanayak et al., 2011; Snyder et al., 2015; Johannessen et al., 2016) for sustaining QoL and wellbeing. Maladaptive cognitions (i.e. catastrophising, overgeneralising, and blaming other), on the other hand, were associated with impaired physical health i.e. fatigue and sleep disturbances (Ali & Bokharey, 2015), while the indirect effect of caregiver burden on mental health is partially mediated by finding

meaning as a way of coping (McLennon et al., 2011). In another study, physical and emotional strain was similarly linked to poor coping mechanisms and excessive caregiving responsibilities, and was exacerbated by the need to overcome obstacles, manage conflicts and improve long-term planning (Alves et al., 2017). Problem-solving strategies (i.e. time management, obtaining instrumental social support - McLeod, 2009), however, had a significant positive correlation with psychological QoL, while dysfunctional coping strategies, such as denial and self-blame, were negatively correlated with both physical and psychological QoL (Hwang et al., 2017). Papastavrou et al. (2011) similarly found that positive coping strategies (i.e. cognitive reappraisal, active problem solving) are correlated with reduced burden, and lower rates of depression. Instrumental (e.g. moving apart from the PwD), cognitive reappraisal (e.g. cognitive distancing from the negative effects of dementia), and emotional coping strategies (e.g. calmer emotional reactions) similarly improved dementia family carers' life situation, when caring for a person with early onset dementia (Johannessen et al., 2016). Controlling upsetting thoughts also mediates the association between negative outcomes and physical health, moderating the association between stressors and positive outcomes (Crellin et al., 2014). Rehman and colleagues found that spirituality as a coping mechanism also reduced strain and improved connection to others, while Häusler and colleagues (2016) found that dyadic coping acts as a mediator on the relationship between stress and QoL in (caregiving) partners of dementia patients.

Eight studies also drew attention to the outstanding support needs of dementia carers (i.e. Kjällman-Alm et al., 2013; Quinn et al., 2015; Johannessen et al., 2016; Alves et al., 2017; Hwang et al., 2017; Wawrziczny et al., 2017; Anderson & White, 2018; McCabe et al., 2018), which included informal community-based (e.g., neighbours, friends, communities), and professional (home and institutional care) respite resources. The consequences of limited family support and inadequate formal support systems challenged dementia family carers' ability to balance the needs of the care recipients with their own (Quinn et al., 2015; Hwang et al., 2017).

These studies outline the significance of coping strategies for the maintenance of QoL and wellbeing outcomes among dementia carers. Moreover, the outstanding support needs of dementia carers can impact the ability of carers to balance their own needs with that of the care recipients, thus impacting dementia carers' ability to sustain their own QoL and wellbeing.

2.3.7 Quality of life and wellbeing of dementia working carers

As with research among DNWC, DWC are negatively affected by greater care-recipient dependence needs, which is exacerbated by the combination of employment with caregiving. Among a sample of 157 carers which included 18 dementia carers, Alpass et al. (2017) found that those who combined work and care had poorer mental health and reported greater depressive symptomatology than non-working carers. In the severe stages of dementia, Nurfatihah et al. (2013) and Wang et al. (2013) found that combined employment and care roles were associated with lower QoL and wellbeing, indexed by mental, physical and general health, and social functioning. In a small qualitative study, Kimura et al. (2015) similarly reported that among dementia carers of early-onset care recipients, dementia caregiving is detrimental to the professional role, physical health, social life, demonstrating a need for more supportive services among DWC. Research (i.e. Hughes et al., 2014) cited by Cheng (2017) also found that the number hours per week caregiving is directly related to the functional dependency of the PwD and missed time at work. Greater caregiving demands have also been associated with poorer psychological wellbeing for carers with high work-life conflict and who are less prepared for high caregiving demands (Wang et al., 2013). For DWC with low work-care conflict, higher preparedness was associated with decreased role strain, even when care demand was high. In corroboration with these findings, Johannessen et al. (2016) in their qualitative study, discussed how resilience and adaptive coping strategies were associated with combining work and care.

In an earlier study by Wang et al. (2011), high levels of workplace flexibility and part-time employment were associated with fewer depressive symptoms for DWC, than among those with full-time jobs. Other studies have also found more positive outcomes for DWC when compared to DNWC. In a study by Välimäki et al. (2009) for instance, sense of coherence was better for women who were DWC. Välimäki and colleagues suggested that work may provide personal fulfilment and provide a supportive social network, while retirement may increase isolation among DNWC. In a qualitative study (Anderson & White, 2018), some DWC discussed how they had learnt to draw boundaries between work and home life, and to seek rewarding work outside of caregiving. Similarly, de Oliveira & Hlebec (2016) found that being employed increases wellbeing, where employed carers had higher levels of satisfaction with life. However, the sample was mixed and therefore it cannot be determined whether this applied to DWC.

These findings imply that DWC coping strategies are particularly significant for sustaining QoL when work-life conflict is minimal. The relationship between caregiving demands and QoL/wellbeing depends on the unique function of work-care conflict, though this can be mediated by greater preparedness for caregiving demands. An increase in preparedness, then, appears to operate in a similar manner to positive coping strategies, protecting DWC with low work and caregiving conflict from increasing care demands. No studies, however, explored the more intricate factors associated with sustained work- life balance for DWC, such as the perceptions of the formal and informal supportive structures used by DWC.

2.4 Discussion

In the context of the rising need for dementia care, reconciling unpaid care and carers' employment is becoming an important social issue. This chapter set out to explore how policies, practice and research have developed in response to the need to support DWC and DNWC. While research with DWC and DNWC was limited, the UK was found to have a cohesive policy which emphasised the promotion of wellbeing of family carers generally in line with social and employment rights. However, in practice, this research falls short in addressing the needs of dementia carers, which could compromise their wellbeing and work and care sustainability. Arguably, to improve practice, practitioners need evidence-based knowledge to assist them to gain a better understanding of wellbeing of DWC and DNWC, to appreciate their social and employment rights. However, few (40) studies explored the QoL and wellbeing of dementia carers. Within those, very few (3 out of 40) focus on DWC and none of those were from the UK. As with the broad definition of wellbeing outlined in the Care Act, the multiple elements of QoL and wellbeing were dominant in the literature among DWC and DNWC, suggesting a complex inter-play of biopsychosocial and mediating factors which strongly correspond to QoL and wellbeing outcomes among DWC and DNWC. Of significance were studies with DNWC that described a positive association between demographic factors (i.e. gender, age, BPSD, carer-dyad relationship) and QoL and wellbeing outcomes. Many studies found an association with mediators of caregiving stress (i.e. coping strategies and instrumental/emotional support) and QoL/wellbeing outcomes. Emotional and instrumental social support and a larger social support

network were associated with a greater QoL. Positive coping strategies (i.e. problem solving, cognitive reappraisal)were also associated with greater QoL and wellbeing outcomes, whilst maladaptive coping strategies (i.e. self-blame, catastrophising etc.) were associated with poor mental and physical health.

Among DWC, the combination of work and caregiving were associated with poorer physical, mental and social functioning, particularly when care recipients were in the severe stages of dementia. For DWC with low work-life conflict and a greater preparedness for caregiving, as well as resilience and adaptive coping strategies, outcomes were more positive, again emphasising the importance of positive coping strategies for DWC. Finally, comparing DWC in full- time employment and DWC who were part-time and had more flexibility in their working time, the latter experienced better mental health. Among DWC at least, it was apparent that instrumental support and coping mechanisms are key to promoting sustainable QoL and wellbeing. These findings highlight well the importance of resilience and role balance for DWC. However, as discussed, the literature on DWC is limited, which means there is a considerable amount that is unknown about the impact of work and care on DWC. Most obvious was the absence of UK studies of DWC, which meant that policy makers, practitioners, and service providers do not have accessible knowledge on DWC to implement relevant policy into practice and to further improve policies. All studies with DWC also did not explore the impact of emotional and instrumental support strategies from family/friends and professional services. Studies that highlighted positive coping strategies, i.e. preparedness, did not clarify how positive coping mechanisms were employed. As studies suggest that the impact of caregiving demands, and positive coping strategies are influential in how dementia carers respond to stress, it is important to address this further with DWC.

Furthermore, while work-life conflict was considered in one study, the bidirectional impact of work-to-life and life-to-work conflict was not. This is a limitation in the literature, since previous research (e.g. Phillips, 1995; Gignac et al., 1996; Allen et al., 2000) has found that the effort involved in maintaining both roles can reduce the performance in both, impacting the overall wellbeing of carers. In this thesis I will address some of the gaps in what is known about the experience of DWC by asking: Do DWC and DNWC differ in QoL; wellbeing; care-recipient status; caregiving experience; psychological resources; social support? What factors are

associated with sustainable wellbeing, everyday functioning and work and life balance among DWC? How do DWC contextualise the experience of work and life balance? What is the relationship between wellbeing, everyday functioning and work and life balance among DWC?

Chapter 3:

Research Methods, Methodology and the Conceptual Framework

3.1 Introduction

As we have already seen in the literature review (Chapter 2), current policies in England, while impressive, do not satisfy governmental requirements to meet the needs of working carers in practice. Furthermore, the extremely limited knowledge of the profiles of DWC in the UK highlights a significant knowledge gap of how DWC interpret their wellbeing when combining work and dementia care roles. This knowledge gap limits care professionals, service providers, and employment sectors understanding of how to support DWC to sustain their wellbeing while remaining in work and caring for a family member with dementia. It is in this vein that this thesis aims to extend empirical knowledge of the factors associated with sustainable wellbeing among dementia family carers who are maintaining employment alongside the caring role. The objectives of this study (outlined in Chapter 1.3) were developed in relation to the current literature (see Chapter 2) and the conceptual frameworks regarding sustainable wellbeing and work-life reconciliation and challenges to sustainable wellbeing and work-life reconciliation among DWC (see Chapter 3.3). The interrogation of these objectives will comprise the overall aim of this research.

In order to achieve these research goals, I first research DWC in comparison with DNWC from the national IDEAL Study, to gain a broader understanding of QoL and wellbeing among DWC. Then, I research a small group of DWC to gain a deeper understanding of their day-to-day work and life experiences which could impact on their QoL and wellbeing.

Before presenting my research findings, it is important to describe the methodologies used in my research in order to provide a transparent account of how I developed the research plan. Therefore, I will begin this chapter by reflectively addressing my own position in this research. This section will be based on my own background and experience, and how this is placed in the specific academic discipline and subject area. Following this, I will explain the theoretical rationale in a conceptual framework, and the methods, methodology and ethical considerations that will be implemented to meet the thesis aims and objectives.

3.2 Researcher reflectivity

While reflecting on this research topic and my role within it, it is important to address my inter-disciplinary role in Social Work and Social Care, and Psychology. My academic background is predominantly in Psychology, having earned a Batchelor's degree at the University of Lincoln in 2008, then going on to study a masters in Mental Health Studies at King's College, London. As a psychological researcher, I was drawn more to the individualistic elements of mental health as opposed to the impact of societal and political changes on groups and individuals, so commonly found in the sociological schools of thought. The potential bias this held was an important and ongoing issue in my research and related to the discrepancy between the study of individual psychological functions, versus the more collective processes based in sociology (Taylor-Gooby & Zinn, 2006). To reduce this bias and enhance my knowledge and skills in the social sciences research, I completed modules in the MSc Social Research Methods course at the University of Sussex in the first year of my PhD. These modules were relevant to policy and practice, and social inclusion in health and social care. It provided me with the foundation to build on the applicability of policies relevant to working carers and their role in society. Furthermore, I completed many other relevant research development courses and presented my research in a wide range of conferences, research seminars throughout my PhD journey, as well as started to submit research findings to academic journals (see Appendix I) to maximise the successfulness of this project completion and its future influence.

My positionality in this project, is related to my feelings about my own background, and current situation. I am from the East Midlands, a mature student, and the only offspring of divorced parents. My own experience, therefore, has been one of a 'divide' in which I have been split between two environments for the best part of 30 years. As both my parents live alone, I have come to think about the prospects that my own future holds, as my role as an intensive primary carer becomes increasingly likely as the parental roles reverse. The conflict this may hold for me whilst still in my early researcher's career is a reality faced by many others in my position. As an older postgraduate student with a central role in both parents' lives, then, my initial interest in the subject was based on an affinity with individuals who would be caring for a close family member, while balancing a career. My main concerns were based on my limited experience in an intense caring role, particularly in dementia care. I felt this could pose a

potential challenge when listening to the experiences of dementia carers. The challenges I envisaged were based on whether I, as a novice researcher with limited real-world experience, could truly be 'with' the carer when they discuss their experiences. My concerns were alleviated somewhat by the fact that experienced researchers will still encounter situations that take them by surprise (Hallowell et al., 2005). At the same time, this 'distance' from the carer's life experience can create a more non-biased, or self-serving role in the subject matter, offering a fresh perspective in which much can be learned and interpreted. Therefore, as the interviewer, I was reassured that my limited exposure to the topic can perhaps be viewed as being of lesser importance (Kajornboon, 2005).

However, while it was sensible to assume that these carers would be facing more extreme difficulties than myself, the conflict I have felt in balancing my professional role with being the sole support system for my parents was exacerbated by living some distance away from both family members. By reflecting on the potential conflicts in my own life, then, it was important to address that the experiences relayed by DWC could present an ethical dilemma if my familial responsibilities clash with my professional role. Fortunately, I have been well prepared in terms of support for such eventualities. Moreover, while it is important to acknowledge that my own experience of providing support and maintaining a professional role can be challenging and distracting, I am also aware that this experience is an integral part of my immersion in the project, and my growth on a personal and professional level.

With that said, I feel my overall position in this research is more clearly concentrated towards my potential future role as a working carer, and my interest in how conflicts between work and life are managed. On this basis, I have come to realise that the increasingly aging population, and uptake of working carers who opt for later retirement, will be a reality faced by many. As a final note, it is reassuring to know that the commonalities of this research to an expanding number of working carers mean that the outcome of this project will be transferable, and potentially transformative, to many more individuals in a variety of contexts.

3.3 Theoretical framework

Based on policies which are designed to protect the wellbeing of carers, the theoretical framework is designed to address those highlighted factors (see Chapter 2.6) which can impact wellbeing and lead to work-life challenges or work-life reconciliation among DWC. In this thesis, the concept of wellbeing among DWC is pertinent to the ethics of care and human needs, whereby sustainable wellbeing is achieved when the needs of DWC are acknowledged.

3.3.1 Wellbeing in the context of care ethics and human need

The theoretical framework for this study begins with the Ethics of Care (Noddings, 1984), which considers the caring relationship in a two-dimensional stance: the needs of the carer and the needs of the care recipient. The normative ethics of care theory alludes to the duty for individuals to support each other with the most basic needs of survival, and to encourage agency through social recognition. The ethics of care also holds a universal commitment to promoting human flourishing (i.e. self-realisation, positive relationships, and life purpose – Gilligan, 1982; Ryan et al. 2008), in line with eudaimonic wellbeing i.e. the pursuit of intrinsic goals and those aspects that contribute to the experience of having a meaningful life (Petterson, 2008). Achieving these intrinsic goals requires the avoidance of self-sacrifice, or the sacrifice of another individual's wellbeing. When people fail to have their fundamental needs met, the result can mean significant harm to the individual and a decline in self-determination (Petterson, 2011). Care ethicists, however, have argued that the balance of care is difficult, since care often takes place under oppressive conditions (Tronto, 1993). Ultimately, then, the ethics of care is concerned with the threats to an individual's wellbeing, including their vulnerability and dependency (Petterson, 2011).

Drawn from social policy and Maslow's theory of need satisfaction, intrinsic goals are embedded in the Theory of Human Need, which is central to the way people conceptualise their QoL (Doyal & Gough, 1991). The Theory of Human Need (Doyal & Gough, 1991; Gough, 2004) elaborates on the promotion of human flourishing in the ethics of care, where human needs are formed from the bases of emotionality in childhood and shape our need for supportive and close relationships and avoiding serious harm. One universal goal of the Theory of Human Need is related to our physical capacity to continue living and function

effectively. The other is for the autonomy of agency to make informed choices about what should be done and how to do it in a given societal context. These basic needs, in turn, require the satisfaction of certain intermediate needs based on areas which include a non-hazardous working and physical environment, appropriate health care, significant primary relationships, and economic security. The premise behind the Theory of Human Need, then, is that our basic needs are universal preconditions that enable us to participate in our own form of life. The ability to meet these basic needs, however, is impaired by poor wellbeing (i.e. severe mental illness, poor physical health and cognitive skills, and difficulties in engaging in social activities- Gough, 2004).

In the context of this study, the principles behind the ethics of care, and the Theory of Human Need, are demonstrable to the wellbeing of DWC, which can be compromised when balancing multiple roles, and cuts to social care funding, resulting in outstanding support needs for care and/or support services (Seddon & Robinson, 2015).

3.3.2 Wellbeing in the context of the challenges of work-life reconciliation

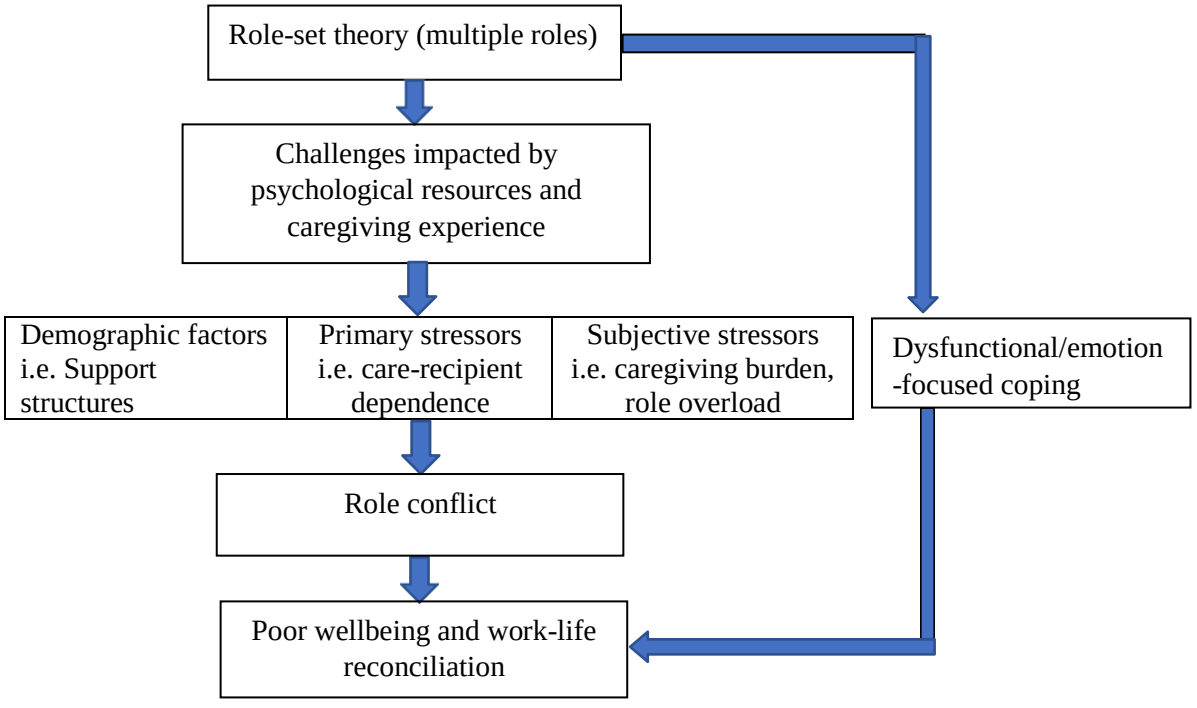
In this section, I describe those factors which can result in poor wellbeing (i.e. low mental and physical health, impaired cognition, and reduced social functioning) outcomes among DWC. For working family carers, multiple roles can impact on self-care and wellbeing (Härter Griep et al., 2016). Role strain occurs as a product of the individual's multiple interests and their navigation through the system of activities (Goode, 1960). Theoretical research towards role conflict has arisen from the study of social structures and relationships, where the distinction between work and home life was reinforced by ‘role-set theory’ (Merton, 1957). Role-set theory recognises that various social arrangements can integrate and challenge the expectations of individuals included in various roles, making conflicting demands difficult. Therefore, role-set theory is concerned with the circumstances that disrupt social functioning, and the social mechanisms that counteract the strains of role-set demands (Merton, 1949). When demands are high for dementia family carers, the Stress Process Model (SPM) (Pearlin et al., 1990) was constructed to describe how stressors lead to poor wellbeing. The SPM proposes that the background context of the carer (i.e. support structures), is related to primary objective stressors (i.e. the dependency status of the PwD). The background context of the carer also affects subjective stressors (i.e. caregiving burden and role overload) which can lead to role strain (i.e. conflict between work, caregiving, and

family/social life), intrapsychic strains (i.e. role captivity, self-esteem) and ultimately, poorer wellbeing (i.e. depression, impaired physical health, and cognitive disturbance).

McLeod (2009) highlighted that emotion-focused coping strategies can contribute to negative outcomes, such as comfort eating, consuming alcohol and drugs (Lazarus & Alfert, 1964), and suppressing emotions. Suppressing emotions over an extended period also compromises immune system competence and can lead to poor physical health (Petrie et al., 1998). Avoidance coping strategies, meanwhile, also have negative effects on health and wellbeing (Ingledew et al., 1997).

The challenges to sustainable wellbeing for DWC therefore, include~~s~~ the challenges of multiple roles, outlined by role-set theory. Multiple roles can impact the personal and psychological resources available to DWC (i.e. poor self-efficacy, low self-esteem, caregiving burden). In the conceptual model outlined below in Figure 3.1, these are arranged according to demographic background factors (i.e. poor social support), primary (i.e. greater care-recipient dependence) and subjective (i.e. role overload) stressors, and maladaptive emotion-focused coping strategies which lead to role-conflict and poor wellbeing outcomes.

Figure 3.1 Conceptual model of challenges to wellbeing and work-life reconciliation for dementia working carers



3.3.3 Wellbeing in the context of sustainable work-life reconciliation

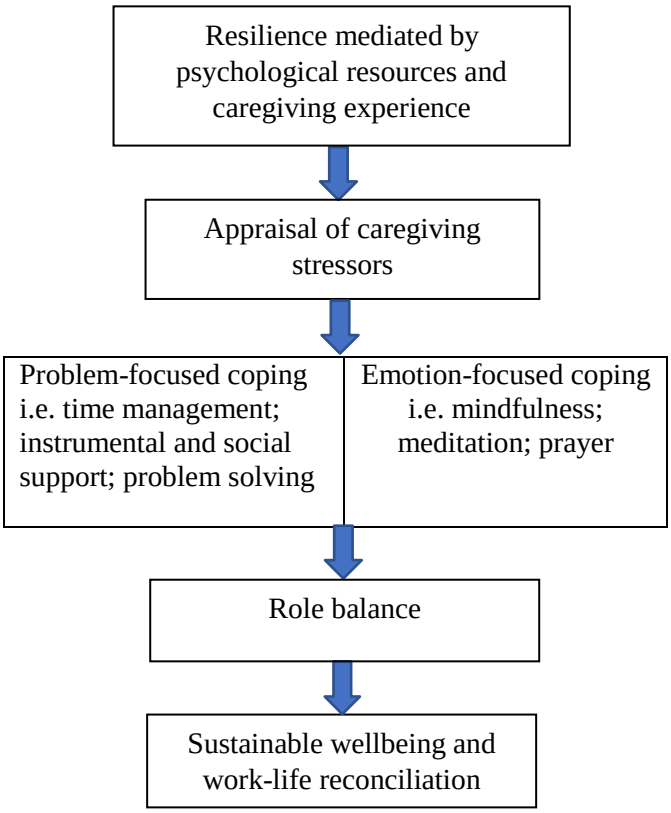
In this section, I describe those factors which can lead to sustainable wellbeing (i.e. good mental and physical health, improved cognition, and social functioning) outcomes for DWC. Research has shown that when it comes to avoiding self-sacrifice and sustaining wellbeing, resilience is a key individual characteristic (Abolghasemi & Taklavi Varaniyab, 2010; Souri & Hasanirad, 2011; Liu et al., 2012; He et al., 2013; Smith & Hollinger-Smith, 2015). Resilience refers to the ability of individuals to face and overcome adversity (Luthar et al., 2000; Campbell-Sills et al., 2007), and the adaptation strategies individuals utilise to cope with discomfort and adversity (Tugade & Fredrickson, 2004; Taormina, 2015). Research has shown a positive association of resilience with eudaimonic wellbeing (Souri & Hasanirad, 2011; He et al., 2013; Smith & Hollinger-Smith, 2015), with regard to the meaning of life and an authentic sense of one's own life (Di Fabio & Palazzeschi, 2015). Donnellan and colleagues (2015) suggest that resilient dementia carers who cope effectively with the demands of caregiving do so because they receive support from family, friends, and respite care services. For individuals with multiple responsibilities, role balance (Marks & McDermid, 1996) is achieved when individuals have the capacity to engage in their roles with equal devotion, attention and care. Role balance is both a behavioural pattern of acting across roles in a certain way and a corresponding cognitive-affective pattern of organising one's inner life of multiple selves, which in turn impacts on whether individuals act with high or low dedication across roles. This increases the potential to achieve role balance or role conflict. People with more balanced role systems, for instance, will report less role strain and depression, greater wellbeing, and higher measures of self-esteem, role ease, and other indicators of wellbeing.

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) is a framework that explains the adaptation strategies for coping with stressful events. This model proposes that adaptation to stress is mediated by two variables: appraisal of the stressor; the individual's coping strategies. These are based on the social and cultural resources at the individual's disposal (Lazarus & Cohen, 1977; Cohen 1984). When faced with a stressor, the individual evaluates the potential threat (primary appraisal) of an event as stressful, positive, controllable, challenging or irrelevant. The second appraisal is the specific coping resources utilised to manage the stressor (Cohen, 1984). Problem-focused coping strategies are aimed at changing a situation which is perceived as stressful and aim

to remove or reduce the cause of the stressor. The strategies associated with problem-focused coping include problem-solving, time-management, and obtaining instrumental social support (McLeod, 2009). Emotion-focused coping strategies are also associated with positive coping strategies such as distraction, prayer, and meditation i.e. mindfulness (Lazarus & Alfert, 1964).

Emotion-focused coping strategies attempt to reduce negative emotional responses associated with stress, such as embarrassment, fear, anxiety, depression, excitement and frustration. When direct action is possible, problem-focused coping has often been found to be superior for handling stress (Lazarus, 1999), and is associated with less depression, fewer physical symptoms (Nakano, 1991), and better QoL (Swindells et al., 1999). Emotion-focused coping has been linked to anxiety, depression, emotional and physical distress (Compas et al., 1996; Nyamathi et al., 1992), and poorer QoL (Swindells et al., 1999). However, in some chronic stress situations, emotion-focused coping can have positive effects on health and wellbeing, such as enhanced perceived social support and reduced depression (Ingledew et al., 1997; McQueeny et al., 1997). Therefore, to achieve balance in one's life, resilience, problem-focused and emotion-focused coping strategies can all contribute to the sustainability of wellbeing in response to challenges. The conceptual model of sustainability outlined in Figure 3.2 hypothesises that more resilient DWC have better personal and psychological resources (i.e. greater self-esteem and self-efficacy, positive caregiving experience). These resources, in turn, enable DWC to use more active coping strategies (i.e. problem-focused coping and positive emotion-focused coping) in response to appraisals of stressors, which lead to greater wellbeing outcomes.

Figure 3.2 Conceptual model of sustainable wellbeing and work-life reconciliation for dementia working carers



3.4 Interdisciplinary and mixed methods research

This study applies a mixed-methods design using quantitative and qualitative data collection methods from the IDEAL data set and my primary data set to capture the experiences of DWC both nationally and locally as well as subjectively and objectively. Using quantitative analyses, the IDEAL Study strengthens the design by enabling a comparison of the wellbeing of a larger national data set of quantitative survey data among DWC and DNWC. The analyses of a primary cohort of DWC, includes both quantitative survey data based on structured interviews, and qualitative semi-structured interviews, which are focused on an artifact representing work-life balance, selected by DWC. The primary data collection strengthens the findings of secondary analyses and provides a rich data set through which further information about the experiences of DWC can be explored. In the final analysis, all methods are merged to develop a more cohesive understanding of how DWC sustain work-life reconciliation.

The interdisciplinary nature of this research is based in psychological and social science disciplines, providing a more holistic perspective from an objective and subjective point of view. The integration of multiple methodologies in psychological and sociological disciplines, for instance, has been affiliated with quite different paradigms - one favouring the postpositivist (quantitative) perspective and the other relying on a constructivist (qualitative) world view (Creswell & Plano Clark, 2007). Becker (1990) for example, highlighted that quantitative methods are often preferred among psychologists, because this approach focuses on asking questions about the reliability and validity of findings. Campbell and Fiske (1959) also discussed the importance of utilising multiple sources of quantitative information to validate psychological traits. Qualitative research, meanwhile, is considered a legitimate form of inquiry for research in the social sciences, where close observations of phenomena are required, as well as uncovering data which is not originally formulated in a research question (Denzin & Lincoln, 2005). Indeed, in some qualitative studies of social phenomena, the ultimate test of the validity of the research is whether it produces an account of social actions that would make sense to the participants themselves (Becker, 1996).

As designs that incorporate quantitative and qualitative methodologies are designed to be especially pliable for lay readers i.e. non-academic audiences (essential for public and policy development: Creswell & Plano Clark, 2011), both methods play a homologous role in this project. Quantitative research entails a deductive approach in the relationship between current theory and research which is geared towards testing theory, as an external objective reality (Bryman, 2012). The major characteristics of quantitative research include: forming predictions or hypotheses; standardised data collection - which is often conducted with a large pool of individuals; statistical analysis, to deliver supportive evidence. Converse to this, qualitative research places an emphasis on words, particularly in the way individuals interpret their social world (Adler & Adler, 1985). Qualitative research is defined by: induction; discovering new information; exploring novel findings; generating theories, and the characteristics of the researcher - the principal 'instrument' in the analytical process (Hall & Howard, 2008). Mixed methods study, therefore, has been advocated as being more fitting for complex research problems (National Research Council, 2002), improving the quality of research (NERF, 2001) and providing a more robust knowledge base to inform theory and practice (Creswell & Plano Clark, 2011).

The mixed methods design selected for this PhD is the parallel-databases variant

of the convergent design. This design has been selected to assist in the development of a working model which synthesises the relationship between variables, to define the properties of sustainability among DWC. In a convergent parallel design, all data can be collected during the same phase and analysed independently. The results from all methods are merged into an overall interpretation to develop a more complete understanding of a phenomenon (Creswell & Plano Clark, 2011). In the social sciences, the term 'triangulation' is used to ascertain how different methods can corroborate or contrast with one another, based on whether the separate results fit into a cohesive outcome, which confirms or revises existing theory (Denzin, 1970). Tashakkori and Teddlie (1998) argue that triangulation designs contribute to research because both quantitative and qualitative approaches are considered equally to understand the object under study. This is achieved by adhering to the rules and assumptions inherent in each method and respecting the contribution of results to the overall research plan (Morse, 1991).

Interdisciplinary research has also become more significant in line with societal and scientific challenges (Hattery, 1979). Johnson and Onwuegbuzie (2004), for instance, stated that interdisciplinary research projects were becoming a growing trend, in conjunction with complex study designs. Along with the richer data set provided by the utilisation of quantitative and qualitative methods of capturing data, interdisciplinary techniques not only encourage the synthesis of disciplines, but also make a truly unique contribution (Jones, 2009) to the research field. The advantages of interdisciplinary research for novice researchers include the opportunities to learn new skills and enhance performance in their field.

Therefore, it is argued that the interdisciplinary nature of research embedded in both psychological and sociological disciplines, provides a statistical and inductive means of exploring the psychological traits and subjective experiences of sustainable wellbeing and work-life reconciliation among DWC. The convergent parallel design in this study provides a strategy upon which the experiences of DWC can be understood from different vantage points based on secondary data in the IDEAL Study, and both quantitative and qualitative primary data, contributing to the development of knowledge.

3.5 Participant selection and recruitment

The participants in this study, including the populations associated with both secondary and primary data sets, are presented in the table below:

Table 3.1 Participants in this research

	Secondary research	**Primary research**	
		Questionnaire	**Interviewing and artifact**
DWC	215	27	24
DNWC	973	N/A	N/A
Location	National	South East	South East
Total	1,238	27	24

The empirical work for the secondary and primary research of this project was carried out within a comparable time frame between December 2017 and August 2018. The secondary research draws from the IDEAL national cohort study consisting of 1,283 dementia family carers (N=215 DWC, N=973 DNWC) across England, under the protocol reported elsewhere (Clare et al., 2014). DWC were classified as carers who were in paid employment and/or voluntary (unpaid) work. DNWC were classified as retired, unable to work, or at home and not looking for work.

Most carers in the IDEAL sample were caring for persons who had been diagnosed with Alzheimer's disease (N=715), with 45 individuals diagnosed with FTD, 142 with Vascular dementia, 263 with mixed dementia, 43 with Parkinson's Disease dementia, 43 with Lewy Body dementia, 27 with unspecified dementia, and 5 with 'other' dementia. The carers who provided care for an individual with FTD were not included in the study. This is related to the increased likelihood of an earlier age of onset and the pronounced behavioural differences in FTD, which could bias the findings. Research indicates greater rates of carer depression and dementia related behavioural challenges in FTD carers (Nicolaou et al., 2010).

All participants in the primary research were based in the South East of England, where there is an intensive ageing population (Office for National Statistics (ONS), 2017)). In addition, they were independent from the IDEAL study, to add additional value to the national project. The original inclusion criteria specified DWC who lived with the PwD and worked and provided care for at least 10 hours a week. Number of hours working and providing care, was based on the guidelines used in previous studies with working family carers (Hoff et al., 2014). Recruiting cohabiting DWC was based on

research which has found that caregiver burden is more likely to occur among family carers who live with the PwD (Spitznagel et al., 2006). However, many DWC approached were unable to work above 10 hours a week due to intense caregiving responsibilities, and vice versa when working roles were demanding. Therefore, to improve recruitment and to fall in line with the inclusion criteria of the IDEAL project, I supported the inclusion of DWC who worked and cared for fewer hours and did not live with the PwD. This was justified on the basis that carers can also experience stress, particularly depression, when care recipients have been placed into full-time professional care (Kong, 2008). In the end, DWC who were working on a voluntary or paid basis, and providing care for at least 4 hours per week, were included in this study. This is because I found

> that many DWC were working for less than 10 hours but more than 4 hours per week during the recruitment process. However, it is worth noting that DWC who are unpaid and in voluntary employment might have more flexibility in their working role and are therefore may be under less workplace pressures than DWC in paid employment. This could mean that DWC in voluntary roles are less representative of DWC generally. Furthermore, including those DWC who work a minimal number of hours (i.e. less than 10 hours on a weekly basis) might introduce higher variance, as those DWC who work greater hours might experience more work-life conflict. (note: these concerns were alleviated in the final primary sample which included only one DWC who was in a voluntary working role, and the majority of DWC were working more than 10 hours a week). Included DWC had a minimum of 1 year in the care role - a decision based on research which has found an association with length of time caring and QoL (McLennon et al., 2011).

Prior to recruitment for the primary study, the study purpose and procedure were clearly explained to the Clinical Research Team Leader (i.e. Sarah Styles) at Sussex Partnership NHS Foundation Trust - my first point of contact for recruitment. I also met with the research team at Brighton and Sussex Medical School, and research nurses of the clinical research network in Kent, Surrey and Sussex (KSS CRN). The final primary sample of DWC were recruited with the support of aging specialists, research assistants via existing databases at Brighton & Sussex Medical School, and a recruitment email (see Appendix II), which was sent within the School of Education and Social Work, and the School of Psychology at the University of Sussex. In addition, posters (see Appendix III) were placed in GP clinic reception areas, support groups, supermarkets, the University of Sussex, and the Brighton Medical School, to reach the desired population. Participants

were also recruited via chance encounters whilst on internal courses organised through the University of Sussex, snowballing sampling, and the Join Dementia Research (JDR) database. All participants were telephoned first with details explaining the study aims and requirements for inclusion. Interested participants were sent an introductory email (see Appendix IV), and a Participant Information Sheet Summary (see Appendix V. Participants who did not express their interest in taking part in this research were assumed to be uninterested in the study and were not followed up. As result, a total of 27 participants took part in the quantitative stages of the study. Within those, 24 participants took part in the qualitative stage of the study. Reasons for the withdrawal of 3 participants from the qualitative stage were based on a change of circumstances (i.e. PwD admittance to intensive care), time limitations, and a preference not to discuss personal experiences in-depth.

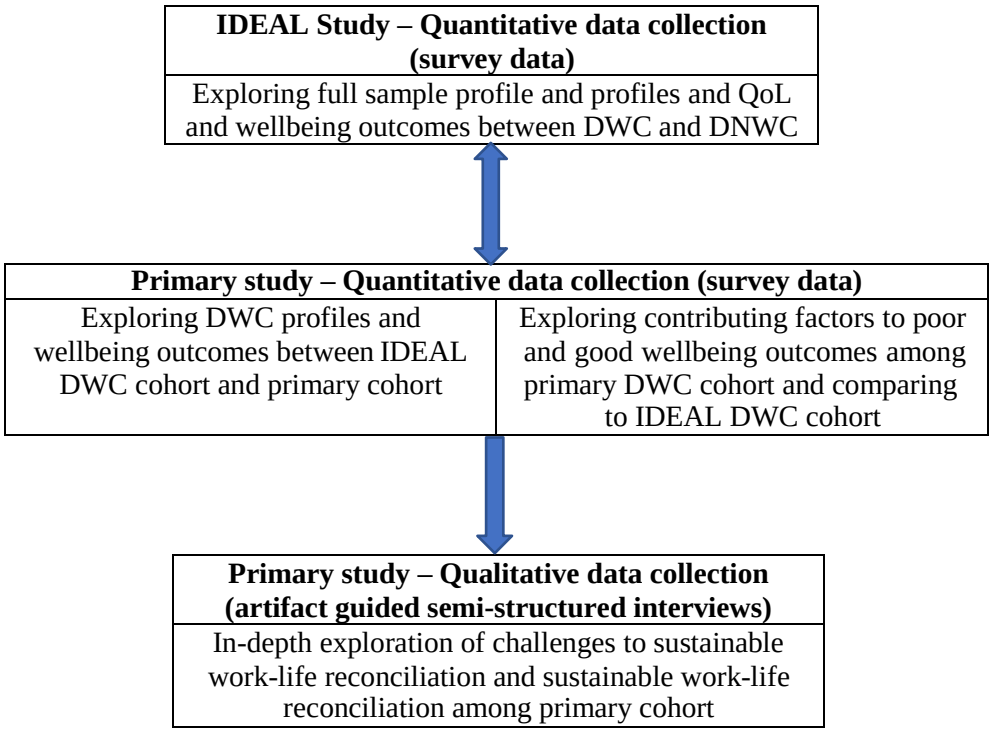
In comparison to the recruitment procedures used in other DWC studies (i.e. purposive sampling - Wang et al., 2011; Nurfatihah et al., 2013; specialist services - Wang et al., 2013; Kimura et al., 2015; secondary data - Wang et al., 2011; Alpass et al., 2017), a wide range of recruitment methods in this study were utilised to reach the desired sample. However, although 24-27 participants in the primary study is relatively small, it is comparable with those studies conducted by other research teams (i.e. Kimura et al., 2015). In comparison to the recruitment size of DWC in the IDEAL Study (n = 215), other studies have also recruited less DWC overall (i.e. Wang et al., 2011; Nurfatihah et al., 2013; Wang et al., 2013; Alpass et al., 2017).

3.6. Data collection: Quantitative and qualitative data collection (IDEAL and primary cohort)

In this thesis, I use multiple means of data collection. These methods comprise: survey data in the IDEAL Study with DWC and DNWC; survey data in the primary cohort of DWC; artifact-guided, semi-structured interviews with the primary cohort of DWC. Quantitative data collected from the IDEAL cohort enable comparisons of QoL and wellbeing outcomes between DWC and DNWC and provides a basis on which contrasts between the profiles of DWC in the national IDEAL Study and the smaller primary sample can be made. Further within group explorations among the primary cohort provides information about the contributing factors to poor and good wellbeing outcomes. Qualitative data enriches the quantitative data, by exploring further those areas of

challenges to sustainable wellbeing and work-life reconciliation and sustainable wellbeing and work-life reconciliation. The diagram in figure 3.3 displays the data collection methods to be used with the IDEAL cohort in this thesis.

Figure 3.3 Data collection methods (IDEAL cohort and primary cohort)



3.6.1 IDEAL questionnaire

For the extraction of secondary data, an IDEAL Main Study Data Request Form was completed (and approved by the IDEAL Project Manager (see Appendix VI). Data was extracted from Time 1 (baseline) of the IDEAL study. To begin with, the following factors were selected to represent the demographic data for dementia carers in IDEAL: a) the diagnoses of PwD; Carer's; b) age, c) gender, d) educational attainment, e) dyad relationship type with PwD, f) daily caregiving hours, g) number of children, h) ethnicity, i) employment status.

Research instruments

The following scales were extracted from IDEAL. A conceptual model of analysis was prepared to reduce the various components identified with QoL and wellbeing outcomes, to a minimal number of observed variables. These variables were organised by: outcome measures; covariate measures; psychological resources; caregiving experience; social support. These measures were specifically selected to map onto the conceptual frameworks of challenges to work-life reconciliation and sustainable work-life reconciliation. As described in Chapter 2, psychological resources and caregiving experiences were found to be important factors in QoL and wellbeing outcomes among DWC and DNWC. Therefore, these were included as preliminary resources which might determine how DWC manage the work-life balance. Several measures were selected to represent psychological resources (i.e. Rosenberg Self-Esteem Scale and General Self-Efficacy Scale) and caregiving experiences (i.e. Role Captivity Scale, Relative Stress Scale, The Positive Aspects of Caregiving Scale, The Management of Situation Scale, and The Caregiving Competence Scale, The COPE Index, Modified Social Restriction Scale, The Short Zarit Burden Interview). As described in the challenges framework and based on the Stress-Process Model, demographic and background factors can influence how DWC appraise primary stressors i.e. care-recipient dependence. Therefore, covariates were selected to explore the impact of demographic factors (i.e. care age, gender, relationship between DWC and PWD, and the dependence needs (i.e. Dependence Scale) of PWD). Moreover, as described in the challenges framework, primary stressors increase the likelihood of subjective stressors (i.e. role overload) and ultimately, work-life conflict among DWC. Therefore, work-life conflict was explored among the primary sample of DWC with the Work-Family Conflict Scale. How DWC cope in the work and caregiving roles (see Chapter 2) was also relevant to the demographic resources at dementia carers' disposal, while social support was also emphasised as important to utilise in the Transaction Model of Stress and Coping. Therefore, social support was explored with the Lubben Social Network Scale-6 and the social relationships sub-scale of the WHOQOL-BREF. As with social support, positive and dysfunctional coping strategies were highlighted as relevant to how DWC manage the work-life balance. In the primary study, coping strategies were explored using the Brief COPE. Measures relating to wellbeing outcomes were represented by both the EQ-5D and the WHO-5 Well-Being Index. As described in Chapter 2, cognitive resources

can also impact the QoL and wellbeing of dementia carers. Therefore, additional measures (i.e. The Attentional Control Scale and Cognitive Failures Questionnaire) explored the everyday functioning of DWC in the primary study.

Outcome measures:

The EQ-5D (EuroQoL Group, 1990): a standardised measure of health status and health outcome, applicable to a wide range of health conditions. The EQ-5D comprises 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The second part of the measure is a visual analogue scale for self-rating of health-related quality of life ('your health state today'). Scores range from 5 to 15. Lower scores indicate a higher QoL. The carer was not asked to provide an informant rating of the visual analogue component of the EQ-5D. *For uniformity in outcome scores, scores have been reversed to indicate higher scores = higher QoL.

WHO-5 Wellbeing Index (Bech, 2004): a short screening instrument for the detection of depression in the general population. The WHO-5 Well-Being Index covers positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things). Scores range from 0 to 25, with higher scores indicating greater wellbeing. A raw score below 13 indicates poor wellbeing. The WHO-5 shows a good internal and external validity with older populations (Heun et al., 2001).

Covariate measures:

- PwD dependence status: *The Dependence Scale* (Brickman et al., 2002): a 13-item questionnaire which measures the amount of assistance needed by the PwD. Scores range from 0 (not dependent at all), to 15 (full dependence). Brickman et al. demonstrated good agreement with measures of cognitive impairment and other functional impairment scales.

-Carer age

-Carer gender

-Carer-dyad relationship type

-Employment status (working/non-working)

Psychological resources:

Rosenberg Self-Esteem Scale (Rosenberg, 1965): a 10-item self-report measure of global self-esteem consisting of 10 statements relating to overall feelings of self-worth or self-acceptance. Scores range from 10 to 40. Lower scores indicate higher self-esteem. *For uniformity in self-esteem scores were reversed to indicate higher scores = higher self-esteem.

Generalised Self-Efficacy Scale (GSE): Schwarzer & Jerusalem, 1995): a 10-item scale designed to assess optimistic self-beliefs (i.e. the belief that one's actions are responsible for successful outcomes) used to cope with a variety of demands in life. Scores range from 10 to 40. Higher scores indicate stronger belief in self-efficacy. Studies have shown that the GSE has high reliability, stability, and construct validity (Leganger et al. 2000; Schwarzer et al., 1999). The scale forms only one global dimension which is equivalent across 28 nations (Leganger et al 2000; Scholz et al. 2002). Relations between the GSE and other social cognitive variables (intention, implementation of intentions, outcome expectations, and self-regulation) are high and confirm the validity of the scale (Luszczynska et al., 2005).

Caregiving experience:

Role Captivity Scale (Pearlin et al., 1990): a 3-item measure designed to assess the extent that dementia carers feel trapped in their role. The total scores range from 0 to 15, with higher scores indicating more role captivity. The scale has a Cronbach alpha coefficient of .84.

The Relative Stress Scale (Greene et al., 1982): a 15-item self-report measure designed to assess the degree of distress and social upset experienced by a relative as the result of caring for a person with physical and/or behavioural difficulties. Total scores range from 0 to 60, with higher scores indicating more severe stress.

The Positive Aspects of Caregiving Scale (Tarlow et al., 2004): a nine-item questionnaire that investigates the positive aspects of being a carer, including whether proving help makes the carer feel useful. The scale ranges from 9 to 45. Higher scores indicate a more

positive caregiving experience. Tarlow and colleagues have reported that the Positive Aspects of Caregiving questionnaire has demonstrated face validity. Caregivers' positive feelings toward caregiving are expected to be positively associated with their level of wellbeing, self-reported health, and satisfaction with received social support, but negatively associated with the amount of burden they feel that caregiving imparts and their dissatisfaction with negative social interactions.

The Management of Situation Scale (Pearlin et al., 1990): a 4-item measure designed to assess the extent that dementia carers feel that they have lost aspects of their personality because of caring. Total scores range from 0 to 12, with greater scores indicating poorer management of situation.

The Caregiving Competence Scale (Robertson et al., 2007): a 3-item measure designed to assess the extent to which dementia carers feel that they are doing an adequate job as a carer. The total scores range from 0 to 15, with higher scores indicating greater competence. The Caregiving Competence Scale has a Cronbach alpha coefficient of .81.

The COPE Index (McKee et al., 2003): a single item global carer coping question
"Do you think you cope well as a carer?" was selected from the COPE Index. The full 17-item Carers of Older People in Europe (COPE) Index, is an assessment of carers' perceptions of their role Scores range from 1 to 4, with higher scores indicating greater coping skills. Construct validity of the instrument has been reported with dementia carers in New Zealand (Roud et al., 2006).

Modified Social Restriction Scale (Balducci et al., 2008): a two-item questionnaire that asks how easy it is for the carer to find someone to look after the PwD if s/he was unwell, and if s/he needed a break from caring. Scores range from 1 'Yes, I could find someone quite easily' to 3 'No, there is no one'.

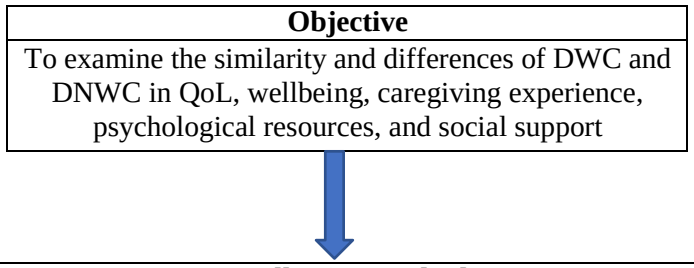
Social support:

Lubben Social Network Scale-6 (LSNS-6 Lubben & Gironda, 2003; Lubben et al., 2006): a six-item scale which is composed of 3 items concerning family and 3 concerning friendships. The LSNS-6 is designed to gauge social isolation in older adults by

measuring perceived social support received by family and friends. The scale is scored out of 30, with a greater score representing greater social engagement. Among three older-adult population samples in European countries, the LSNS-6 overall, and both subscales (Family and Friends) demonstrated high levels of internal consistency, stable factor structures, and high correlations with criterion variables for the assessment of those at risk of social isolation. Proposed clinical cut-points also show good convergent validity (Lubben et al., 2006).

WHOQOL-BREF – Social relationships (Skevington et al., 2004): an instrument comprising 26 items, which measure the broad domains of: physical health, psychological health, social relationships, and environment. For the purposes of this study, I extracted two questions relevant to social relationships to explore how satisfied carers are with their social relationships and the support they get from friends. Scores range from 1 to 5, with higher scores indicating greater satisfaction with social relationships and support. Analyses of internal consistency, item-total correlations, discriminant validity and construct validity, indicate that the WHOQOL-BREF has good to excellent psychometric properties of reliability and validity. Figure 3.4 outlines the objective for exploring sustainable QoL and wellbeing among the IDEAL cohort and the data collection method to explore sustainable QoL and wellbeing.

Figure 3.4 Objective and data collection methods (IDEAL cohort)



Data collection methods				
		SAPPR		
Demographic data	**QoL and wellbeing outcomes**	**Caregiving experience**	**Psychological resources**	**Social support**
PwD diagnoses; Age; Gender; Education; Carer-dyad relationship type; Daily caregiving hours; Number of children; Ethnicity; Employment status for DWC and DNWC	EQ-5D; WHO-5 Well-Being Index	Role Captivity Scale; Relative Stress Scale; Positive Aspects of Caregiving Scale; Management of Situation Scale; Caregiving Competence Scale; The COPE Index; Modified Social Restriction Scale	Rosenberg Self-Esteem Scale; Generalised Self-Efficacy Scale	Lubben Social Network Scale-6; WHOQOL-BREF (Social relationships)

3.6.2 Primary questionnaire

The demographic questions in the primary questionnaire were identical to those in the IDEAL project to maximise the opportunity to compare the two groups. Two additional questions explored DWC weekly working hours and reduced working hours. Six questionnaires were selected from the IDEAL study to present to the primary sample. In selecting the overlapping instruments extracted from IDEAL, we adhered to the recommendations of the Ethical Committee and PPI input, which was guided by the potential stress that some of these instruments may *cause* to participants, in addition to limitations on time with the primary sample of DWC. Therefore, the instruments selected from the IDEAL study were chosen because they took limited time to implement and

represented well the core factors explored in the IDEAL study. The Positive Aspects of Caregiving Scale was specifically selected as a recommendation by the PPI, to ensure that a positive indicator of wellbeing was included in the questionnaire to reduce potential carer stress from too many negative items. In line with the categorisation of instruments used in the IDEAL study, a) the Dependence Scale represented care-recipient dependence, b) the Role Captivity Scale, c) Positive Aspects of Caregiving Scale, d) Management of Situation Scale, and e) Caregiving Competence Scale represented 'caregiving experience', and f) the WHO-5 Well-Being Index was selected as the outcome measure, in line with the focus of this thesis on wellbeing, and the emphasis on carer wellbeing in the Care Act. In addition, the following instruments were added to further explore indices of wellbeing associated with caregiving experience; coping strategies; everyday functioning; the bidirectionality of life-to-work and work-to-life influences (note: the following instruments were excluded from the final analysis to reduce overlap with IDEAL measures and items used with the primary cohort to represent care-recipient dependence, caregiving experience, work and life balance, and wellbeing: Functional Activities Questionnaire (FAQ); Maslach Burnout Inventory; The Job Satisfaction Subscale of the Michigan Organizational Assessment Questionnaire); Short-Form Health Survey (SF-12); Center for Epidemiologic Studies Depression Scale Revised (CESD-R-10)).

Research instruments

Caregiving experience:

The Short Zarit Burden Interview (*ZBI: Be dard et al., 2001):* a 12-item questionnaire which was developed from the Burden Scale for Family Caregivers. The score ranges from 0 to 30. Higher scores indicate greater caregiver burden. The internal consistency of the questionnaire is strong (Cronbach's alpha 0.77). Yu et al. (2018) found that the short ZBI also demonstrated the excellent convergent validity with dementia carers and provided evidence to confirm similar findings (Tang et al., 2016).

Coping strategies:

The Brief COPE (Carver, 1997): a 14-item questionnaire measuring coping strategies which consist of composite subscales measuring emotion-focused, problem-focused, and dysfunctional coping. Emotion-focused strategies consist of: acceptance (accepting the reality that it has happened/learning to live with it); emotional support (getting emotional support, comfort and understanding); humour (making fun of the situation); positive reframing (trying to see a problem in a different light/make it seem more positive); religion (finding comfort in religious or spiritual beliefs/praying or meditating). Problem-focused strategies consist of: active coping (concentrating efforts on doing something about the situation); instrumental support (getting help and advice from other people); planning (trying to come up with a strategy about what to do). Dysfunctional coping strategies consist of: behavioural disengagement (giving up trying to deal with it); denial (refusing to believe it has happened); self-distraction (turning to work or other activities to avoid thinking about a situation); self-blame; substance use (using alcohol or other drugs to get through it); venting (expressing negative feelings). Cooper et al. (2006; 2008) used the Brief COPE with dysfunctional, problem-focused or emotion-focused subscales in a study of dementia carers. Cooper and colleagues (2008) demonstrated good internal consistency and construct validity, and adequate test-retest reliability of the Brief COPE when operationalised as 3 subscales, although the correlation of emotion-focused coping scores measured a year apart was modest.

Everyday functioning:

The Cognitive Failures Questionnaire (*CFQ: Broadbent et al., 1982*): a scale consisting of 25 items. Total scores range from 0 to 100, with higher scores indicating greater cognitive failures. High CFQ scores have been related to constructs such as accident proneness, human error, and psychological strain (Bridger et al., 2013). The CFQ is also a measure of attentional control which is borne by research indicating that the scale is correlated with objective indices of attention (Manly et al., 1999; Robertson et al., 1997). The CFQ has been employed in a broad range of clinical and non-clinical populations and has high construct validity (e.g. Wallace et al., 2002; Wallace & Vodanovich, 2003).

Attentional Control Scale (ACS): a scale consisting of 20 questions. Total scores range from 20 to 80. Higher scores indicate greater attentional control. The ACS was designed to capture the respondent's perceived ability to focus their attention, and to flexibly control thought (Derryberry & Reed, 2002). Derryberry and Reed reported that the internal consistency for the ACS total score was .88. Moreover, Matthews et al. (2004) found that higher ACS scores were associated with higher levels of activation in brain areas related to regulation of emotion (Crouch et al., 2012).

Family-to work, Work-to-family conflict:

Work-Family Conflict Scale (*Carlson et al., 2000*): an 18-item scale with six different subscales that measured the six dimensions of work–family conflict: time-based work interference with family (WIF); time-based FIW (family interference with work); strain-based WIF; strain-based FIW; behaviour-based WIF; behaviour-based FIW. Scores range from 18 to 90. Higher scores indicate greater conflict. Each of the scales in the six-dimensional model has shown discriminant validity, internal consistency, and in-variance of the factor structure across samples (Fornell & Larcker, 1981). Greenhaus and Beutell (1985) highlighted that time-based conflict can occur when time devoted to one role makes it difficult to participate in another role. Strain-based conflict is experienced when the strain of one role interferes with participation in another role, while behaviour-based conflict occurs when behaviours required in one role are incompatible with the behavioural expectations in another role. Scales which have not taken this multidimensional approach have been considered as ineffective in capturing the multiple challenges associated with balancing work and family life (Netemeyer et al., 1996; Stephens & Sommer, 1996).

Open-ended questions:

Open-ended questions included in the IDEAL study were adapted for use in the primary study and were added to the end of the structured questionnaire. The inclusion of five open-ended questions provided DWC with an opportunity to elaborate on the answers provided. The diagram in figure 3.5 outlines the objective and data collection methods for exploring sustainable wellbeing, everyday functioning, and work and life balance among the primary cohort of DWC.

Figure 3.5 Objective and data collection methods (primary cohort)

Objective
To define the factors that are associated with sustainable wellbeing, everyday functioning, and work and life balance among DWC

Data collection methods					
				SAPPR	
Demographic data	**Wellbeing outcomes**	**Everyday functioning**	**Work and life balance**	**Caregiving experience**	**Coping strategies**
Age; PwD diagnoses; Gender; Carer-dyad relationship type; Education; Daily caregiving hours; Occupational profile; Weekly working hours; Reduction in working hours; Ethnicity	WHO-5 Well-Being Index	Cognitive Failures Questionnaire; Attentional Control Scale	Work-Family Conflict Scale	Role Captivity Scale; Positive Aspects of Caregiving Scale; Management of Situation Scale; Caregiving Competence Scale; The Short Zarit Burden Interview	COPE Index i.e. Problem-focused; Emotion-focused; Dysfunctional

3.6.3 Primary artifact elicitation and interviewing

After completing the structured interview, participants received detailed instructions (verbally and in writing) (see Appendix VII) for selecting an object to represent their experience of work and care, and a date and place arranged for the individual semi-structured interview. One week before the meeting, participants were sent a follow-up letter by email or post (see Appendix VIII) to thank them for their participation in the structured interview, and to remind them about the arranged follow-up visit. The Participant Information Sheet Summary and Photography Consent Form were also re- sent as a reminder of the study procedure, and to ensure participants were still happy to continue.

At the beginning of the interview, I asked participants to discuss the object they had selected to represent the work-life balance. This was followed by the semi-structured interview exploring:

- How sustainable balance between work and care could be achieved;
- Why a conflict could occur between work and care;
- What care and support services at local and national level could assist DWC with work and care reconciliation.

Based on the narrative collected through the interview process, I decided which prompts on the interview schedule had been covered and which prompts I needed to use in cases where verbal information was less forthcoming. Following the interview, participants were asked to use the researcher's smart phone to take several pictures of the artifact. They were then asked to select the picture they preferred and reasons for selection in case there were any additional insights about the artifact, not covered in the interview. Each interview lasted for an average of one hour and was digitally recorded.

I applied a solution-focused approach when framing the interviewing questions to focus on the strength of the individuals and explore potential routes to improvement of their wellbeing as DWC. The solution focused approach to interviews stems from the use of solution focused brief therapy as a strengths-based approach which emphasises the individual's resources and how these can be applied as a positive change. Solution focused techniques, therefore, focus on strengths in life rather than a detailed analysis of problem dimensions (DfE, 2011), and have been successfully applied across a range of contexts and client groups, including professionals and community members (DfE et al., 2008; Corcoran & Pillai, 2009). Semi-structured interviewing (Berk, 1994) has also been considered the most suitable technique in a research area where pre-existing knowledge is limited, and the topic of interest may be particularly sensitive. While interviews are often a co-production between interviewer and interviewee, the advantage of semi-structured interviews is that co-production can be guided by the interviewer or the interviewee (Adams, 2010).

Furthermore, the interviews incorporate an anthropological, creative element into the study, by centring on an artifact selected by the DWC to represent their work and life experiences. Artifact elicitation facilitated discussion by enabling the carer to reflect, through an object of personal importance, their own experiences of combining work and

care. The introduction of an artifact to represent a research question is a relatively under-utilized approach to gaining knowledge about participants' experiences, although this creative method of qualitative data collection has several advantages over traditional face-to-face interview techniques. For example, Rouse (2013) explained that the use of images can place control over the interview process by the participant, bringing out issues that are meaningful to them (Frith et al., 2005). This method also elicits details that might otherwise be difficult to talk about, leading to the disclosure of more sensitive and emotional details (Bagnoli, 2009). This is especially the case where the individual experience of DWC could be emotional and private. These examples have led to an increasing acceptance that visual methods can provide rich and valid data about issues of concern to the social sciences for understanding the construction of a particular reality, where attention is paid to what is made visible and what remains hidden (Frith et al., 2005). Elicitation interviews usually use a visual artifact to help gain a direct understanding of the participant's views on an abstract topic, and can embody the knowledge, skills, and attitudes held by the artifact creators and encourage critical thinking (Douglas et al., 2015).

Therefore, the introduction of artifact-guided semi-structured interviews provided participants with an opportunityto discuss the more meaningful experiences of work-life reconciliation, whilst enhancing existing knowledge. As the solution-focused elements of the interview were also focused on existing and required resources of support, this information can be used to invoke a positive change for DWC, which can inform decision-making in commercial and public sector contexts (Pink, 2004).

3.7 Primary data pilot testing

This study involved secondary data analysis from the IDEAL project. In addition, it involved recruitment and testing of a primary sample to add value to the analysis of the IDEAL dataset. Having designed the primary research which included a questionnaire (see Appendix IX) and interviewing schedule with artifact (see Appendix X), I then piloted these with the Patient and Public Involvement (PPI), Dementia Consultation Group on 16 April 2016, and on 21st June and 5th July 2016 with one DWC who is a member of a service user and carer advisory group at the Department of Social Work and Social Care, the University of Sussex. Initial testing proved that both structured (i.e. questionnaire) and semi-structured interviews (i.e. interviewing schedule with artifact

elicitation) lasted just over one hour. During the structured interview, initial impressions showed that the carer appeared to be comfortable with the questions, apart from finding some questions and prompts 'repetitive'. Changes to semi-structured interviews were minimal and were centred on how prompts relating to work-life reconciliation and work-life conflict were phrased. The main amendment suggested by the carers were that some questions and prompts in the structured interview could enquire about whether any other areas of the participant's life were affected, instead of how they were affected as a carer or employee. Below, I outline the strengths and weakness of the questionnaire and interviewing schedules with artifact elicitation, and the changes put into place to reduce the identified weaknesses.

The strengths of the structured interview were related to the flexibility of the open-ended questions following structured questioning. These questions provided an opportunity for the participant to elaborate on the advantages of caring and softened the structured nature of questionnaires. The participant also felt that the interview sections were well organised and supported the delivery and flow of the interview. The main challenge of the structured interview for the participant, were that some questions were difficult to provide just one response to. This was particularly significant for the Functional Activities Questionnaire, where some questions asked about multiple abilities of the PwD e.g. D5. Can your relative/friend heat water for coffee or tea and turn off the stove?

The advantages of the semi-structured interview were that the participant felt able to disclose more information than allowed by the structured interview. The participant was also highly enthusiastic about relaying the positive and negative experiences of balancing work and care. The final closing question (i.e. Would you like to expand on any other areas of work and life balance in dementia care that you feel are important, but have not been discussed?), provided the participant with the freedom to address any other matters that they felt the semi-structured interview did not cover. However, the 'flow' of the information provided by the participant was initially difficult to monitor.

Consequently, this impacted on following whether the participant had sufficiently covered the main questions in each section of the interview schedule. Therefore, the first testing of the interview meant that all prompts were utilised, as the participant reverted between successful and unsuccessful examples of work and life balance. According to the participant, the main challenge of the semi-structured interview, was the subtle variation between prompts, which meant that some questions seemed repetitive.

These findings resulted in the following changes to the delivery of the interview schedule:

- If a participant is struggling to commit to a response in structured interviews, ask them to provide the closest answer that is true for them. If there are no suitable response options, then label the response as missing data;
- Put successful and unsuccessful examples of work and care reconciliation prompts side by side in instances where participants might drift between positive and negative aspects of the work and life balance;
- Distinguish between prompts to ensure the requirements of the question are more transparent;

If the participant feels that a question has already been asked, provide them with an option to elaborate broadly on other areas of their life which are affected.

3.8 Methodology for coding and analysis

In this section, I describe how the data is clustered and analysed for the quantitative data collected for both the IDEAL and primary cohort. Finally, I explain the qualitative data analyses for the semi-structured interviews with the primary cohort.

3.8.1 Examining the similarity and differences in reported quality of life and wellbeing between dementia working carers and dementia non-working carers

For the first quantitative data chapter (Chapter 4), preliminary analyses established the demographic factors (i.e. dementia diagnoses; age; gender, carer educational attainment; carer-dyad relationship; daily caregiving hours; number of children; carer ethnicity), associated with the full IDEAL sample of DWC and DNWC, using descriptive and frequency analyses using the IBM Statistical Package for the Social Sciences (SPSS: Version 24). The full sample was then split by employment status according to whether carers were working (i.e. ‘In paid employment’ and ‘Doing voluntary (unpaid) work’)), and not working (i.e. ‘Retired’, ‘Unable to work’, ‘At home and not looking for work’). Using independent samples t-tests and Pearson’s Chi-Square tests (Field, 2013) for continuous (age) and categorical data (dementia diagnoses, gender, carer-dyad

relationship), working and non-working groups were compared according to the demographic factors outlined in the first stage of analysis. In the next stage of analysis, DWC and DNWC were compared according to total scores on outcome and covariate indices, care-recipient status, and self-assessed psychological and personal resources (SAPPR) i.e. psychological resources, caregiving experience, and social support. T-tests and Pearson Chi-Square tests were used to explore group differences.

In the next stage of analyses (Chapter 5) the contribution of covariates (i.e. age, gender, carer-dyad relationship, care-recipient dependence, and working status) and independent variables associated with SAPPR (i.e. psychological resources; caregiving experience; social support) were explored between DWC and DNWC. Firstly, bivariate correlations (Field, 2013) between measures (excluding outcomes measures of QoL and wellbeing) were performed to determine whether there is an empirical relationship between all independent variables. A multivariate analysis of covariance (MANCOVA) was then run with EQ-5D and WHO-5 as the dependent variables, controlling for covariates (i.e. age, gender, carer-dyad relationship and care-recipient dependence), to determine whether working status significantly predicted variance of QoL and wellbeing outcomes.

Subsequently, a series of univariate multiple regression models were created to identify the variance accounted for by working status on each outcome.

3.8.2 Exploring self-assessed psychological resources, caregiving competence. and the bidirectional impact of work-life conflict among dementia working carers

The final quantitative chapter (Chapter 6) combined and explored data collected from the IDEAL and the primary sample. I began by comparing the demographic variables for DWC in the IDEAL sample and primary cohort (i.e. age, dementia diagnoses, gender, carer-dyad relationship, education, daily caregiving hours, occupational profile, weekly working hours, reduction in working hours, and ethnicity), using descriptive and frequencies in SPSS to ascertain how representative the primary sample were of the larger IDEAL sample demographic.

I then analysed total scores from the overlapping measures in the IDEAL study, to assess how comparable the broader profiles of the carers in the primary sample were to the full and sub-sample of DWC in the IDEAL cohort. Using independent samples t-tests (Field, 2013), comparisons were made on total scores for: WHO-5 (wellbeing);

Dependence Scale; Management of Situation Scale; Role Captivity Scale; Positive Aspects of Caregiving Scale; Caregiving Competence Scale. Following this, I extracted total scores among the primary sample which were based on: care-recipient dependence (i.e. Dependence Scale); caregiving experience (i.e. Management of Situation Scale; Positive Aspects of Caregiving Scale; Role Captivity Scale; Caregiving Competence Scale; Short ZBI (personal strain and role strain)), coping strategies (i.e. Brief COPE Index (Emotional, Problem-focused, Dysfunctional coping strategies); family-to work/work-to family conflict (Work-Family Conflict Scale); everyday functioning (i.e. CFQ, ACS), to gain further insight about other indicators of wellbeing among the primary sample of DWC. The primary cohort was stratified by wellbeing scores - those with scores associated with poor wellbeing (i.e. scores below 13) and those with scores associated with higher wellbeing - to explore the following:

- Are wellbeing outcomes associated with: care-recipient dependence; caregiving experience; coping strategies; work-to-family, family-to-work conflict; cognitive functioning?

Comparisons between groups based on poorer and higher wellbeing were made using independent samples t-tests; this is appropriate for ordinal data where there is normal distribution of scores (see Chapter 6 (Field, 2013)). As a general rule, the significance level for parametric tests is most commonly set at 5% and therefore, the confidence level is 95%. (Field, 2013).

While the findings from the IDEAL cohort also found a significant effect of age and gender in the difference between the QoL of DWC and DNWC, these were not explored in the primary sample due to the sample size of the primary dataset.

3.8.3 Contextualising dementia working carers' experience of sustainable work and life balance

The qualitative data chapters (Chapter 7 and 8) were derived from interviews with the primary sample. The interviewing data were analysed using qualitative content analysis, which is most often applied to verbal data such as interview transcripts (Schreier, 2012). In qualitative content analysis, data can be reduced to concepts that describe the research phenomenon through the creation of categories, concepts and conceptual maps (Elo &

Kyngäs, 2008), where the interpretation of data is presented in words and themes (Bengtsson, 2016). A 'theme' is an overall concept of an underlying meaning to answer a research question (Graneheim & Lundman, 2004). Themes located across the information described and organised how various strategies were used by DWC for work-life reconciliation and the daily challenges they experienced with combining work and care roles. The entire data set of 24 interviews relating to the artifacts selected by DWC were studied together, with initial ideas and impressions of the data noted.

In deductive reasoning, hypotheses or principles are explored via predetermined, existing subjects (Berg, 2001; Polit & Beck, 2006). I began by applying the conceptual framework associated with *challenges* and *sustainability* of wellbeing and work-life reconciliation as discussed in Chapter Three. These concepts were deductively generated from the theory and prior research which evidenced that dementia working carers might face *challenges* in sustaining their work and life balance but could make efforts to find a way to *sustain* their multiple roles and their wellbeing.

Initially, participants' descriptions of their selected artifact were categorised according to how the object represented challenges to work-life reconciliation, and how it was used to achieve sustainable work-life balance among DWC. To analyse the artifact, I applied a neutral perspective using manifest analysis to ensure that my views of the artifact would stay close to the original meaning and contexts of the participants (Burnard, 1991). Another advantage of manifest analysis is that while it is necessary for the researcher to continuously refer back to the original text, this thoroughness assists in describing the visual and obvious meanings in the artifact while using the participant's own words (Berg, 2001).

For the analysis of the interview transcripts, I began with following the stages of content analysis described by Bengtsson (2016), which involves immersing myself in the data to the extent that I am familiar with the breadth and depth of the content. This procedure required that I, the researcher, read the whole transcriptions many times to obtain the whole sense of each transcript before choosing the parts of transcriptions which seem to contain relational aspects (i.e. 'challenges' and 'sustainability') that answered the questions set out in the aim of the study (Graneheim & Lundman, 2004) and associate the conceptual framework developed in Chapter Three (see Appendix XI). Quotes referring to challenges and sustainability from interview transcripts were copies and pasted into an excel table, chronologically in interviewee order. I then labelled coded ideas in relation to the context of the research - described as the "open coding process" (Berg, 2001). In the analysis of

data, these codes facilitate the identification of concepts and ideas (Catanzaro, 1988). After the coding and conceptualising process, codes with the same characteristics were grouped under a category/theme, which is another abstraction of these concepts. I applied different ways of naming a category/theme to reflect the participants' voice (see Polit & Beck, 2012; Saldana, 2012). This included some categories/themes came from my insight into what was happening in portions of data (e.g. organisational skills, see Chapter 8.5). Others were gathered from established terms used in the literature (e.g. caregiving burden, see Chapter 7.5).

Once codes were clustered inside categories/themes, the properties and dimensions for each category/theme (and its subcategories/sub-themes) were defined (see Appendix XII). Appendix XIII shows how data was further reduced to more concise themes (and sub-themes). The themes (and sub-themes) were checked by the first supervisor – Dr. Henglien Lisa Chen to ensure inter-rater reliability and agreement on theme selection (Boyatzis, 1998). Furthermore, to validate the outcome and to strengthen the validity of the study, I performed a respondent validation in which participants were presented with a transcript of their interview and a draft of my findings in Chapter 7 and Chapter 8 in order to achieve agreement (Burnard, 1991). This ensured that I had not misinterpreted the participant's voice.

3.9. Ethical considerations

Much effort was put into the ethical considerations from the outset of my PhD journey, reflecting the complexity and scale of the research project. In this section I discuss my ethical approval process and then highlight the key ethical considerations which I found the most important for completing the fieldwork successfully.

3.9.1 Ethical approval

A highly comprehensive process for obtaining ethical approval for the primary research in this project was necessary due to the sensitive nature of interview topics relating to dementia care, and in line with the NHS duty of care to service users (i.e. the DWC) who are recruited as participants in research projects (Health Research Authority (HRA), 2018)). Therefore, ethical approval for the primary research in this study was, firstly, gained from the NHS Health Research Authority approval (HRA REC reference:

16/EM/0383, see Appendix XIV) on 27 October 2016, followed by Research Governance approval at the University of Sussex (see Appendix XV) on 24 November 2016. The HRA research ethics application prompts detailed ethical consideration, including but not limited to confidentiality, potential harm to participants and conflicts of interest (see thesis IRAS application: Appendix XVI). This comprehensive process for the ethical approval ensured that the study design had been thoroughly vetted to certify that the safety of participants in the study would not be compromised. In addition, the study was eligible for inclusion on the NIHR portfolio (Ref: CPMS 33132). As a result, I received support from NHS research nurse teams to reach the desired sample of DWC. The Letter of Access to approach clinical research centres for recruitment was received on 24 November 2016 and expired on 25 November 2017, by which time all participants had been recruited.

The secondary research approval was gained by the North Wales Research Ethics Committee - West (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL study is registered with UKCRN (registration number 16593). The transfer of secondary data from the linked Living Well with Dementia study was approved by the ethics committees (see IDEAL IRAS application: Appendix XVII) prior to study commencement, and by participants for scholarly and educational purposes (see IDEAL Consent form: Appendix XVIII).

3.9.2 Informed consent

The study requirements and procedures for the primary study were explained to participants beforehand in the Participation Information Sheet Summary, Participant Information Sheet – Full version (see Appendix XIX) and were further clarified in person. The principle of informed consent has become seminal in the codes and guidelines of the British Sociological Association (2017). It is argued that fully transparent information about the research is essential, so the participant could make an informed choice about whether they want to take part in the study. On the day before each scheduled interview/survey, I contacted each person again to check that they still wished to have a meeting, as an on-going process of informed consent. This gave all the potential participants the opportunity to decline to be part of the study without me being physically present, and time to decide whether they were comfortable sharing their experiences with

someone they hardly knew. The process of consent ensures that people – vulnerable ones in particular – have plenty of opportunity to be reminded of and understand what they were consenting to. This was very important for DWC in the present research, as they were potentially experiencing some work and care difficulties in the process of needing time for themselves. Participants found my written and verbal instructions were clear and easy to understand and they could make an informed choice about taking part. Participants were aware and understood that they could withdraw consent from the study at any time, and request that their data is withdrawn and destroyed as stated in the Participant Information Sheet Summary and Participant Information Sheet

During the first meeting with the participant, informed consent was formally gained for the first stage of the study in an Informed Consent Form (see Appendix XX) as well as a Photography Consent Form (see Appendix XXI) for photographing the artifact in the second stage of the study. Participants kept one copy of the forms for themselves, while another copy was retained by me securely for the study records.

3.9.3 Confidentiality

Confidentiality is crucial in research, especially for DWC who shared their experience of work and care which involved their personal view of their families, care professionals, agencies, and their colleagues and employers. To ensure the identity and data of participants was protected, procedures were put in place. For example, physical data, such as signed consent forms and completed questionnaires, were stored in separate lockable filing cabinets to avoid linkage of personal information to data generated by the study. Personal details (i.e. participant ID numbers, addresses and telephone numbers) were stored on encrypted files which were emailed through a protected university email account by recruitment teams, following the NHS Code of Confidentiality (DoH, 2003) to ensure the security of personal information is maintained. Participants were reassured that the tape transcriptions would be done by me and that all details related to the study would be kept confidential. They were also assured that all personal data, recording files, field notes, survey response, and interview transcripts were retained on the university password protected database, which is only accessible by me and my supervisors. In addition, none of the personal information would be discussed beyond myself and my supervisors. At each interview, it was made explicit that the working survey, transcripts and tapes would be kept until completion of the dissemination of findings and then

destroyed. All participants were offered a copy of their survey and interview transcript. Only one participant asked for a copy and it was provided.

Participant confidentially was also maintained by the allocation of anonymised participants' information with a Participant ID number. This ID number eliminated the chances of participants being personally identified from any data source, so that the information they provided remained confidential. Similarly, direct quotes from interviews were edited to ensure that no information which could lead to identification was used in publications or academic presentations. Furthermore, the first draft of the typed interview transcripts was provided to the participants, first, to ensure that the confidentially is applied adequately in the publication, and second, to ensure that I have not mis transcribed or misinterpreted their voice.

3.9.4 Potential harm to participants and researcher

The protection of participants' safety and welfare was another issue which was highlighted in the ethics application and in consultation with a Dementia Consultation Group. For this study, this meant that the questions posed in the structured and semi-structured interview relating to personal experience of work and care might be distressing. Therefore, participants were informed in the Participant Information Sheet and explained face-to-face that they do not have to answer questions they would prefer not to. During the interviewing, I paused (or stopped completely) when discomfort was apparent. The interview approach worked at the pace of the individual participants. Prior to taking part, participants were also informed that there was some risk of emotional distress and that I (the researcher) took the responsibility in line with good research practice (The British Psychological Society, 2009) to inform a designated professional if there were significant concerns for their wellbeing. I researched and prepared for a list of relevant care professional contacts prior to the fieldwork and there were a few occasions following the interviews that I called on the debriefing, input and advice of one or both study supervisors as required. This occurred in some cases when DWC highlighted the need for signposting to carer's assessment procedures and emotional support.

The potential benefits and risks to participants were identified by a Dementia Consultation Group on 6th April 2016 (see Appendix XXII for recommended study design changes). Feedback relevant to modifications to the study design was acted upon (see Appendix XXIII for modifications to the study design). Based on the guidance of the

group, instructions provided at the beginning of each questionnaire were delivered in a way to soften the questions which followed. Likewise, questionnaires were purposely designed to end on a positive note by pertaining to the positive aspects of being a carer. The participant was given an option of taking breaks from the interview as many times as they liked. This ensured that the participant felt in control of the interviewing and all of them were fully engaged with the study with no need for follow up interviewing. To make the interviews as comfortable as possible, each stage of the study was conducted in an environment chosen by the participant (e.g. their own home, local pubs, coffee shops near to their workplace).

As with participant safety, the safety of the researcher was also accounted for. Prior to fieldwork, supervisors were fully informed of the location, participant's contact detail and the expected time of arrival and departure by the researcher. A text was sent to the supervisors within half an hour of the anticipated time of arrival and departure from locations. If a text was not received, the supervisors would follow up with a telephone call. The strategy provided me with personal safety provision and reassurance as a lone worker in the fieldwork. In the event, no interventions were required by the supervisors. Furthermore, I took the opportunity in each post-interview period to check in with supervisors in order to reflect on the interviewing process and findings in the first instance to maximise my engagement with my fieldwork development.

3.10 Summary

This chapter contains the method and methodology to be used in this research. Building on what is already understood about sustainable wellbeing and threats to sustainable wellbeing among DWC and DNWC, the sustainability framework demonstrates the importance of resilience, problem-focused and emotion-focused coping strategies, for the sustainability of wellbeing in response to challenges to work-life reconciliation. The challenges (to sustainability) framework highlights that multiple demands of conflicting roles, demographic factors (i.e. background context), primary (i.e. PwD dependence), subjective (i.e. role overload) stressors, and maladaptive coping strategies, can contribute to poor wellbeing among DWC, and the experience of poor work-to-family and family-to-work conflict. The conceptual frameworks and background research in Chapter 2 provide the basis on which the research aim and objectives were developed for this study. Based on the theoretical framework outlined, the quantitative

and qualitative strands of the mixed-methods study design describe how the research objectives outlined in Chapter 1 will be met. Based on good research practice, the ethical considerations outline measures taken to protect participants in the design of the structured and semi-structured interviews. As with the potential risks this study posed to participants, it was also necessary to describe provisions which reduced the risks to my own mental health and safety, during fieldwork.

Chapter 4:

Demographic profile and comparison of self-assessed psychological and personal resources between dementia working carers and dementia non-working carers

4.1 Introduction

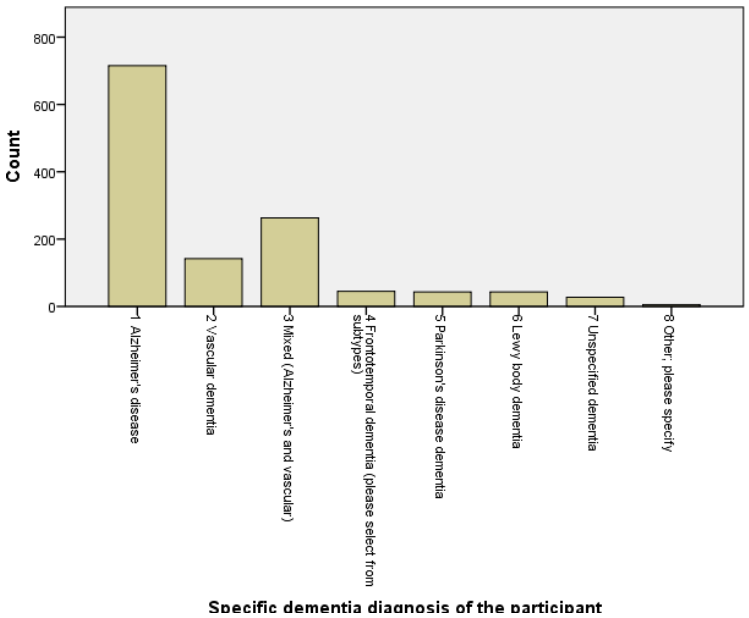
As argued in Chapter 2, dementia carers are not a homogeneous group. Therefore, to gain a better understanding of the diversity of this group, this chapter generates the characteristic of DWC and DNWC from secondary national data. In this chapter, I present the demographic profile of the full IDEAL cohort, and then the comparison of the DWC and DNWC demographic profile in this cohort. Following this, the quantitative exploration for the secondary analyses of factors associated with QoL, wellbeing, care-recipient status, psychological resources, caregiving experience, and social support among DWC, were completed on data extracted from time 1 (baseline data) of the IDEAL cohort study (Clare et al., 2014). Finally, I will compare the two groups to identify whether DWC and DNWC differ in QoL, wellbeing, psychological resources, caregiving experience, and social support.

4.2 Part 1: Profile of the full carers sample in the IDEAL cohort

Dementia diagnosis of the person with dementia

Several specific dementia diagnoses were represented in the IDEAL cohort.

Histogram 4.1: Dementia diagnosis

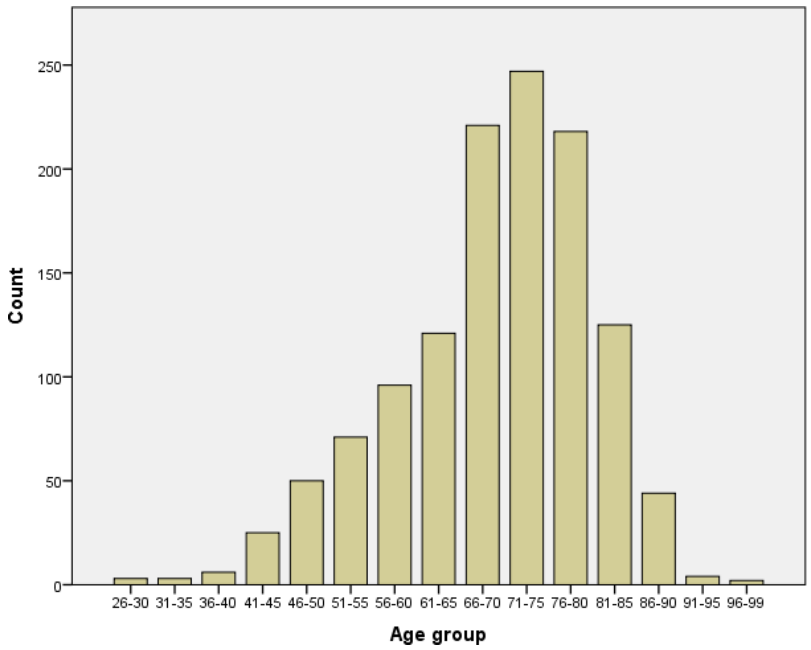


The majority of carers in this sample were caring for persons who have been diagnosed with Alzheimer's disease (N=715), with 45 individuals diagnosed with FTD, 142 with Vascular dementia and 263 with mixed dementia (Histogram 4.1). The diagnosis of FTD is the only early onset dementia included in this sample, and this could introduce potential confounds based on their distinct behavioural profile, including greater rates of carer depression and dementia related behavioural challenges (Nicolaou et al., 2010). Forty-five of the IDEAL cohort carers were caring for people with FTD, and these were excluded from further analyses. The decision was therefore made that this group should be excluded from subsequent analyses for this thesis. All subsequent references to "the full IDEAL cohort" will therefore refer to the full cohort after the exclusion of the FTD group.

Carer Age groups

Histogram 4.2 shows the frequency data based on age for all carers. The original IDEAL syntax by 'age', was categorised in 5 year 'bins'. Appendix XXIV shows a detailed breakdown of age in the IDEAL sample (note: 2 individuals did not provide age data and therefore were not included in this descriptive).

Histogram 4.2: Age group of carers



As seen in the above histogram 4.2 based on age group, there is a wide dispersion and a normal distribution across age categories. Carers in this sample are predominantly in the older age categories of 66 to 80 years of age. The mean age of the carer sample was 69.31 years.

Gender of carers

The frequency table (4.1) shows that most carers are females (68.7%). This difference matches population norms according to the distribution of gender among carers generally (Carers UK, 2013).

Table 4.1: Frequencies – Gender distribution of carers

		Frequency	Percent
Valid	Male	387	31.3
	Female	850	68.7
	Total	1237	99.9
Missing	System	1	.1
	Total	1238	100.0

Education level of carers

I explored the distribution of level of education across carers. There were 82 (6.8%) carers assigned to 'other' in the 'Level of education' variable, which was associated with qualifications and could not be assigned to a category i.e. army certification.

Table 4.2: Frequencies – Level of education

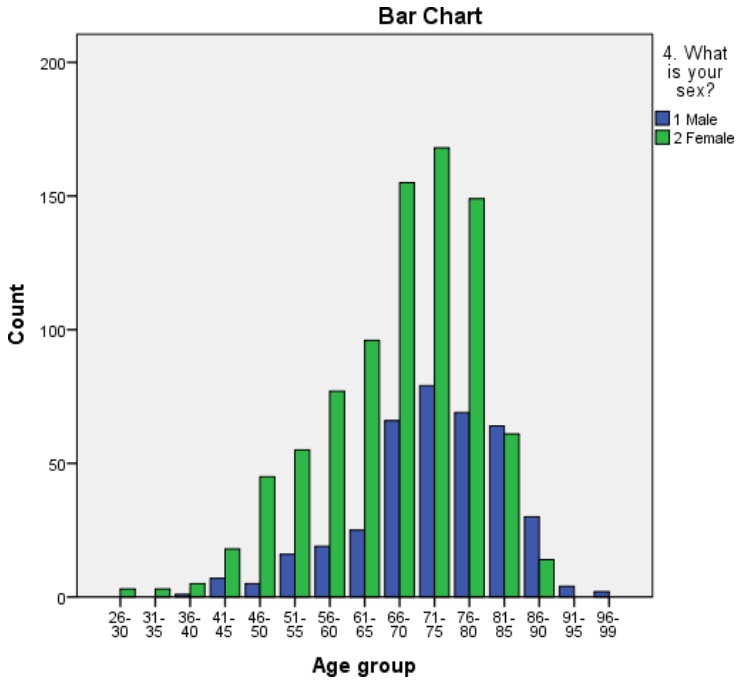
		Frequency	Percent
	No formal qualifications	263	21.2
	GCSEs or equivalent (O levels, CSEs, School Certificate, Standard Grades)	263	21.2
	Completed apprenticeship	69	5.6
	A levels or equivalent (Leaving Certificate, Higher Grades)	83	6.7
	National Vocational Qualification	87	7.0
	Higher National Diploma	82	6.6
	Undergraduate degree (BA, BSc)	201	16.2
	Master's degree (MA, MSc)	49	4.0
	PhD	17	1.4
	Other; please specify	82	6.6
	Total	1196	96.6
Missing	System	42	3.4
	Total	1238	100.0

As shown in Table 4.2, most carers (70.8%) in this sample had a standard level of education (i.e. below undergraduate degree).

Age group x Gender

Using cross-tabulations, I isolated descriptives according to Age group and Gender.

Bar chart 4.1: Age group x Gender



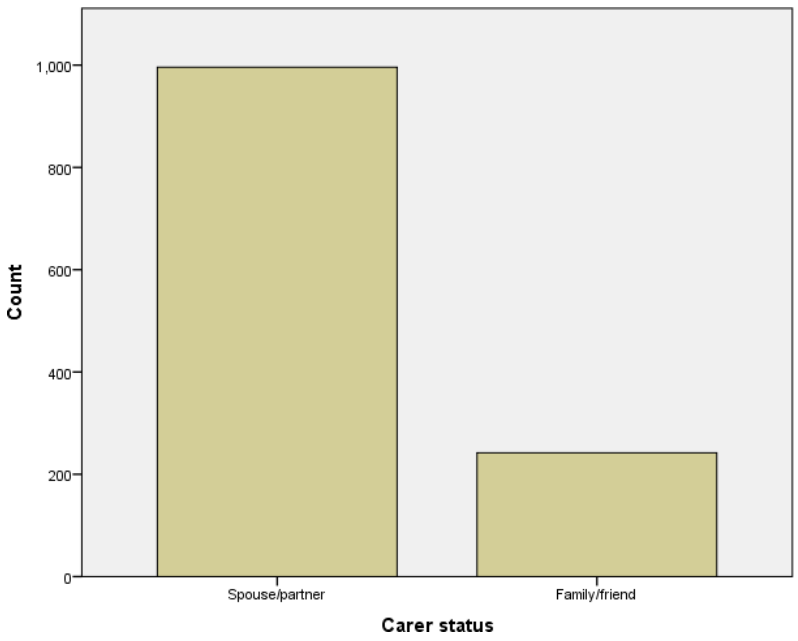
The bar chart (4.1), shows a normal distribution between males and females and their age group.

In summary, most carers in the IDEAL cohort are in the 66 – 80 age categories. A higher percentage of carers are female (68.7%). Across all age categories in the IDEAL cohort, most carers have a standard level of education.

Carer dyad relationship

The relationship between the carer and PwD was explored.

Histogram 4.3: Carer-dyad relationship



The histogram (4.3) shows a greater number of spousal/partner carers in the IDEAL cohort (80.5%), than other family/friend carers.

Daily caregiving hours

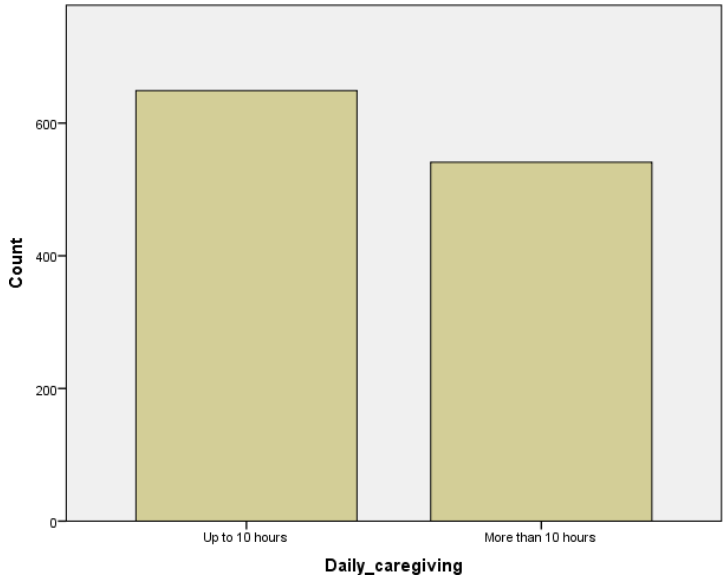
A full summary of daily hours of care are displayed in Table 4.3.

Table 4.3: Frequencies – Daily caregiving hours

		Frequency	Percent
	Provide no help in a typical day	80	6.5
	Less than 1 hour	143	11.6
	More than 1 hour and up to 2 hours	134	10.8
	More than 2 hours and up to 3 hours	97	7.8
	More than 3 hours and up to 5 hours	104	8.4
	More than 5 hours and up to 10 hours	91	7.4
	More than 10 hours, but not overnight	54	4.4
	More than 10 hours and/including overnight	400	32.3
	Other	87	7.0
	Total	1190	96.1
Missing	System	48	3.9
	Total	1238	100.0

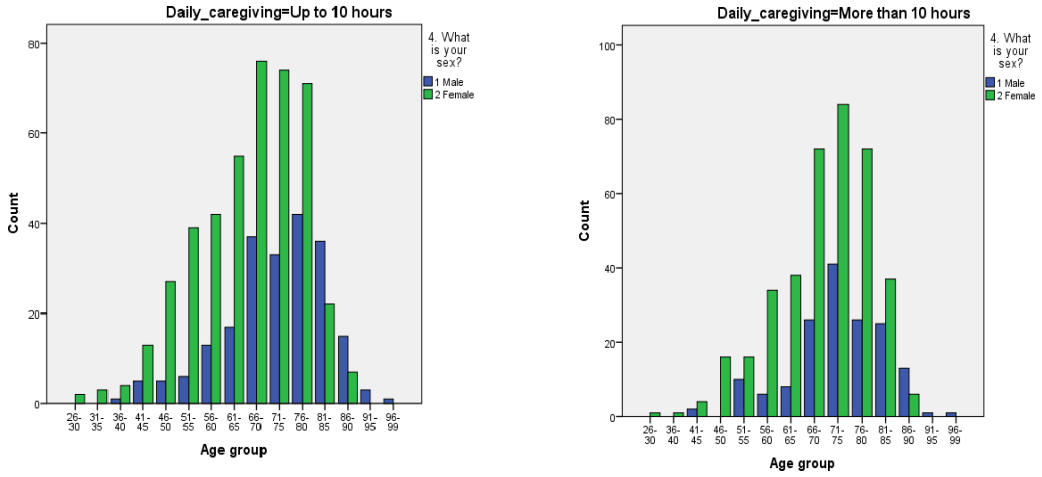
To simplify analysis, carers were re-categorised into 2 groups – those who provide care for up to 10 hours daily; those who provide care for more than 10 hours daily (including those who provide overnight care). As 7% of carers in the 'other' category could not be assigned to either group, they were excluded from this stage of the analysis.

Histogram 4.4: Daily caregiving hours



The histogram (4.4) shows that most of the carers in the IDEAL sample are providing care for up to 10 hours. Using cross-tabulations, I then explored how daily caregiving hours are distributed between age group and gender (bar charts 4.2).

Bar charts 4.2: Daily caregiving hours x Age group x Gender



The bar charts (4.2) show that most carers are providing daily care ≤ 10 hours and are mostly female (68.6%). The average age of carers who provided daily care ≤ 10 hours is around 68 (mean age 68.09) and those providing daily care > 10 hours are around 70 (mean 70.56 years). This was a significant difference between groups: t (1187) = -3.83, p = < .001 (two-tailed). However, there was no significant difference between gender and daily care which is provided ≤ or > 10 hours: t (1188) = -1.327, p = > .05.

Children

The number of children in carers' families was also investigated across the whole sample to provide an insight into carers' other potential caregiving obligations (Table 4.4). NB: the data collected in the IDEAL study did not provide the ages of carers' children, which could have provided a potential insight of the additional caregiving responsibilities among younger and mid-age carers, who are more likely to have younger children with higher dependency needs (Depasquale et al., 2016).

Table 4.4: Frequencies – Number of children

		Frequency	Percent
Valid	None	128	10.3
	One	166	13.4
	Two	536	43.3
	Three	253	20.4
	Four	104	8.4
	Five	25	2.0
	Other	17	1.4
	Total	1229	99.3
Missing	System	9	.7
	Total	1238	100.0

Secondary descriptives (ethnicity)

Secondary descriptives relating to ethnicity and level of spoken English were briefly explored for the whole sample. Most carers in the IDEAL sample are White (English/Welsh/Scottish/Northern Irish/British - N=1228 = 96.2%) and spoke English as their first language (98.4%); those carers whose first language was not English (N=19), had a good standard of spoken English (see Appendix XXV).

4.2.1 Interim Summary: Profile of the full carers sample in the IDEAL cohort

Based on the demographic variables shown for the whole sample in the IDEAL cohort, the predominant diagnosis for the PwD is Alzheimer's disease. There are a greater number of carers who are female, spouses, and who are in the older age groups. The next part of analysis will compare demographic variables between DWC and DNWC.

4.2.2 Dementia working carers versus dementia non-working carers in the IDEAL sample

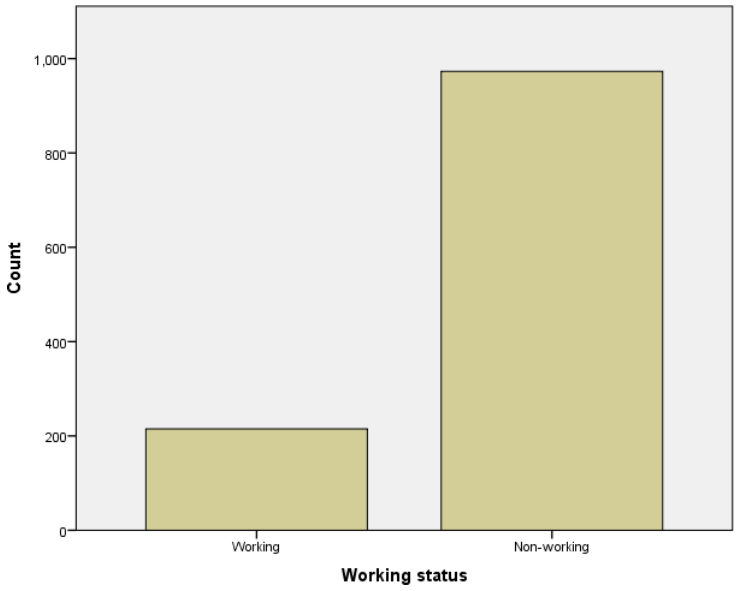
For the purpose of this thesis, "Working" in this sample was defined as paid and voluntary employment. "Non-working" was defined as those carers who were retired, unable to work, unemployed and looking for work, at home and not looking for work, and students (full and part time).

The frequency table (4.5) and histogram (4.5) demonstrate that there were a greater number of DWC (973), than DNWC (215) in this sample (note: 50 (4%) of individuals did not provide employment data, and one individual did not provide age data; therefore, these carers were not included in this descriptive)).

Table 4.5: Frequencies – Dementia working carers versus dementia non-working carers

		Frequency	Percent
Valid	DWC	215	17.4
	DNWC	973	78.6
	Total	1188	96.0
Missing	System	50	4.0
	Total	1238	100.0

Histogram 4.5: Dementia working carers versus dementia non-working carers

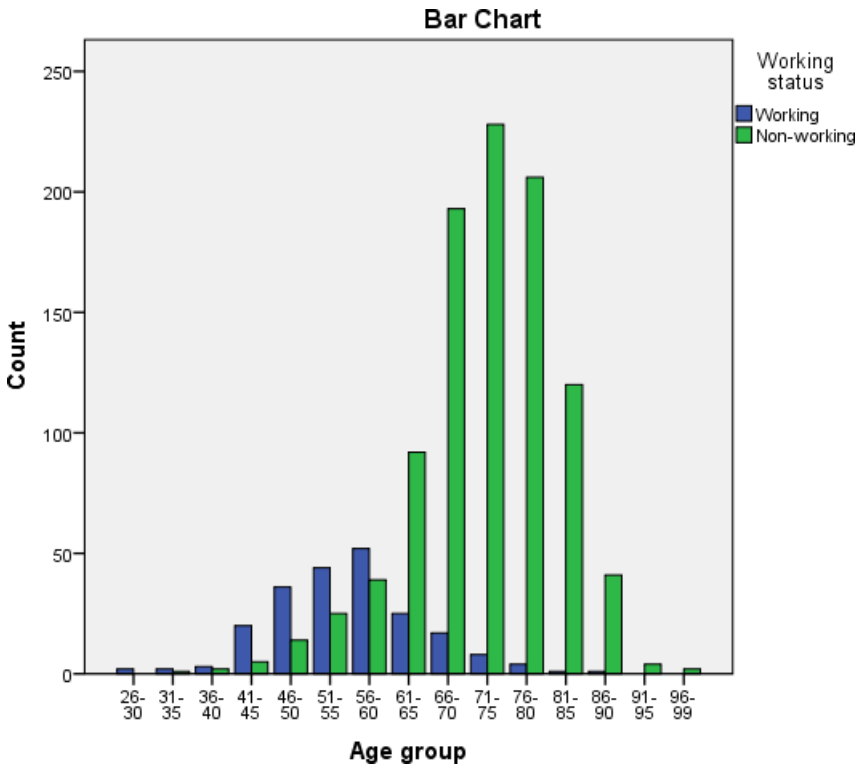


Dementia working carers versus dementia non-working carers: Age group

The bar chart (4.3) show a considerably higher number of DNWC in the older age category of 71 to 75 (mean 72.3) years, with DWC age peaking around 56 to 60 (mean 55.5) years. This was a significant difference between groups: t (1185) = -24.31, p = <

.001 (two-tailed). A chi-square test of independence confirmed that the age distribution of DWC and DNWC is unequal: X2 (62, N = 1187) = 565.64, p = <.001.

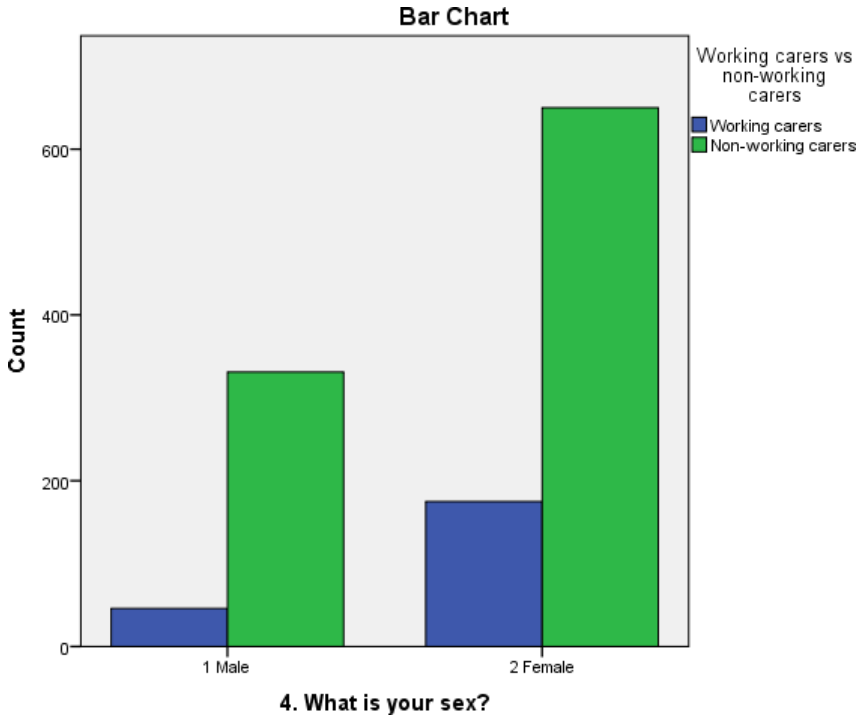
Bar chart 4.3: Age group



Dementia working carers versus dementia non-working carers: Gender

The bar chart (4.4) shows a considerably higher number of DWC (170) and DNWC who are female (647), than DWC (45) and DNWC (326) who are male.

Bar chart 4.4: Gender

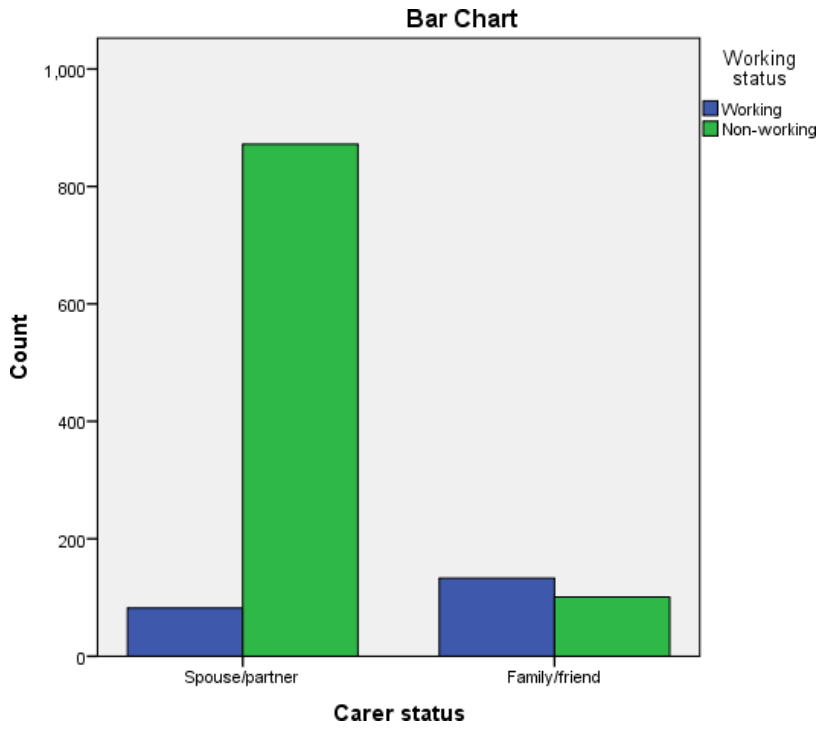


The chi-square test further confirmed that the distribution of gender between DWC and DNWC is unequal between groups: X2 (1, N = 1188) = 12.96, p = <.001.

Dementia working carers versus dementia non-working carers: Carer-dyad relationship

The carer-dyad relationship was then explored between DWC and DNWC.

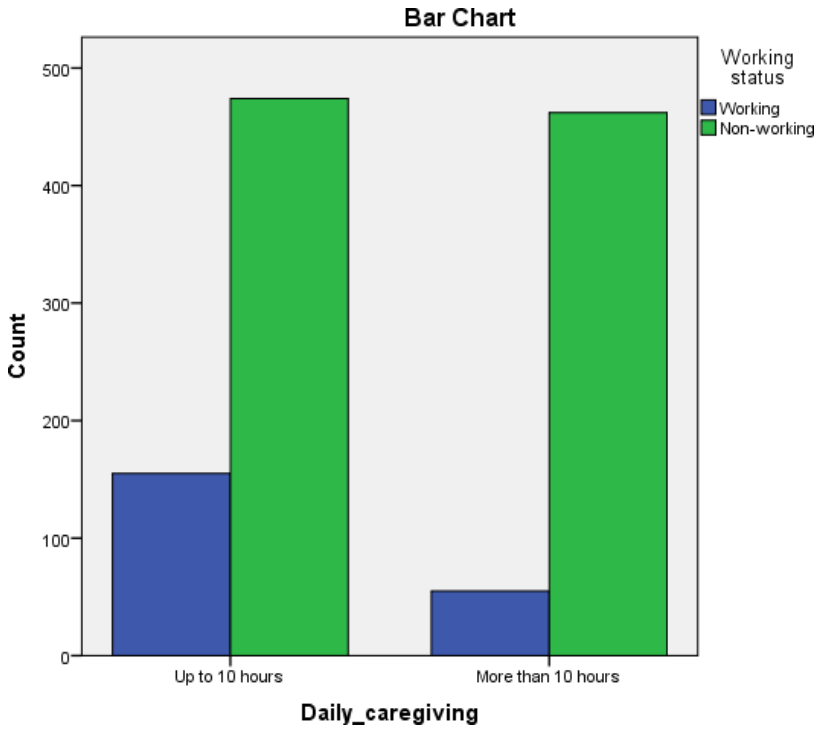
Bar chart 4.5: Carer-dyad relationship



The bar chart (4.5) shows that there are a considerably greater number of DNWC who are spouses of PwD (73.4% of total sample), but between DWC, a similar number are a family/friend carer of PwD

Dementia working dementia carers versus dementia non-working carers: Daily caregiving hours

B**ar chart 4.6:** Daily caregiving hours



The bar chart (4.6) shows a similar number of DNWC provide daily care up to (474) and above 10 hours (462). More DWC provide daily care up to 10 hours (155) than above 10 hours (55). The chi-square test confirmed that the distribution of caregiving hours between DWC and DNWC is unequal between DWC who provide ≤ or > 10 hours of daily care: X2 (1, N = 1146) = 37.18, p = <.001.

4.2.3 Interim Summary: Dementia working carers versus dementia non-working carers in the IDEAL sample (demographics)

The comparisons of demographics between DWC and DNWC in the IDEAL cohort show some important differences. In this sample, a greater number of the DNWC fall in the older age groups, while the DWC peak around the age of 55. Further, most DNWC are spouses, while DWC have an almost equal chance of being a spouse or a family/friend of the PwD. DWC and DNWC however, are similarly more likely to be

females. Comparison of caregiving hours between DWC and DNWC also showed that DNWC are closely split between those providing daily care up to or over 10 hours, while DWC are more likely to be providing less than 10 hours of daily care.

4.3 Part 2: Quality of life and wellbeing, care-recipient status, self-assessed psychological and personal resources for the full IDEAL sample

The next stage of the analysis of the IDEAL T1 data was to explore total scores and subscale scores between DWC and DNWC, based on instruments that have been selected to measure:

1. Quality of life: EQ-5D
2. Wellbeing: WHO-5 Well-Being Index
3. Care-recipient status

First, I addressed the following question: Do DWC and DNWC differ in QoL; wellbeing; care-recipient status; caregiving experience; psychological resources; social support?

Total and subscale scores associated with QoL and Wellbeing were compared between DWC and DNWC using t-test comparisons.

4.3.1 Quality of life: EQ:5D

The total score on the EQ-5D indicates health-related QoL: this was reverse scored so that the higher the score, the better the subjective QoL. Scores overall ranged from 5 (the worst health state) to 15 (the best health-state). The mean score for QoL among carers in the IDEAL cohort was 8.46. The mean total scores for the EQ-5D (Table 4.6) between DWC (M=9.16, SD=1.13) and DNWC carers (M=8.31, SD=1.58), demonstrated that DWC report a better QoL than DNWC. An independent t-test confirmed that this was a significant difference between groups: $t(1160) = 7.45$, $p = <.01$ (two-tailed).

Table 4.6: EQ-5D mean total score – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
EQ-5D total	DWC	214	9.16	1.13	.07
	DNWC	948	8.31	1.58	.05

4.3.2 Wellbeing: WHO-5 Well-Being Index

I explored general wellbeing using the WHO-5 Well-Being Index. Total scores ranged from 0 to 25, where scores below 13 indicate poor wellbeing. The mean score for wellbeing among carers was 13.82. Table 4.7 shows mean total wellbeing scores between DWC (M=14.15, SD = 4.60) and DNWC (M=13.82, SD = 4.96); independent t-test confirmed that means were not significantly different between groups: t(1152) = .877, p = >.05.

Table 4.7: WHO-5 Well-Being Index – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
WHO-5 total	DWC	208	14.15	4.60	.31
	DNWC	946	13.82	4.96	.16

4.3.3 Care recipient status

I explored dementia carers' reports of PwD functioning, as an indicator of the status of PwD, which may contribute to the QoL and wellbeing reported by the carer.

Dependence Scale

The scale ranges from zero, meaning not dependent at all, to 16, which would indicate full dependence. Across the sample, the total carer-rated assessment score of PwD dependence was 5.63. Table 4.8 shows the dependence needs of PwD between DWC (M=5.65, SD = 2.49) and DNWC (M=5.64, SD = 2.62). Independent samples t-

test confirmed that the dependence ratings between groups was not significantly different: t(1113) = .075, p = >.05.

Table 4.8: Dependence Scale – Dementia working dementia carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Dependence total	DWC	198	5.65	2.49	.17
	DNWC	917	5.64	2.62	.08

4.3.4 Interim Summary: Quality of life and wellbeing for the full IDEAL sample

Measures associated with QoL and wellbeing between the full sample of DWC and DNWC show that the cohort are above mid-range for both QoL and wellbeing. DWC and DNWC differ in their QoL scores only, with DWC reporting higher QoL scores than DNWC. The two groups were comparable in terms of the level of dependence of the PwD being cared for.

4.3.5 Self-assessed psychological and personal resources

The IDEAL database includes a number of measures provided by the carers that have collectively been called "self-assessed psychological and personal resources" (SAPPR). These allow us to quantify the resources that the carers bring to the task of caring, and include items which are relevant to psychological health, coping, and appraisals of the restrictive/positive aspects of caregiving.

In this next section, I compared the full IDEAL sample of DWC and DNWC on selected SAPPR, using t-tests. The selected measures were:

1. Psychological resources i.e. Rosenberg Self-Esteem Scale; Generalized Self-Efficacy Scale);
2. Caregiving experience i.e., Role Captivity Scale; Relative Stress Scale; Positive Aspects of Caregiving Scale; Management of Situation Scale; Caregiving Competence Scale); COPE INDEX (single item); Modified Social Restriction Scale;

3. Social support i.e. Lubben Social Network Scale-6; selected questions from the WHOL-BREF social relationships sub-domain.

Where necessary, individual scales were reverse scored so that in all cases, the scoring is intuitively directional i.e. greater QoL scores represent higher QoL and higher self-esteem score equals higher self-esteem.

4.3.6 Self-assessed psychological and personal resources – Psychological resources

Self-esteem: Rosenberg Self-Esteem Scale

The total scores on this (reverse scored) scale ranged from 10 to 40, with higher scores indicating greater self-esteem. The total mean score for self-esteem among carers was 21.16. Table 4.9 shows rated self-esteem between DWC (M=21.42, SD = 4.67) and DNWC (M=21.14, SD = 4.48). Independent samples t-test showed that between groups this was not significantly different: t(1129) = .811, p = >.05. These results are somewhat lower in comparison to other findings (Schmitt & Allik, 2005) which show that self-esteem measured by the Rosenberg Self-Esteem Scale is generally above the theoretical mid-point, where the authors suggested that generally, positive self-esteem is culturally universal and higher in individualistic than collectivist cultures.

Table 4.9: Rosenberg Self-Esteem Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Self-esteem total	DWC	205	21.42	4.67	.32
	DNWC	926	21.14	4.48	.14

Self-efficacy: Generalized Self-Efficacy Scale

Perceived self-efficacy scores range from 10 (low perceived self-efficacy) to 40 (high perceived self-efficacy). The total mean score for perceived self-efficacy among carers was 31.61. Table 4.10 shows that rated self-efficacy is higher among DWC

(M=32.57, SD = 4.20) than DNWC (M=31.38, SD = 4.27). Independent samples t-test showed that this difference was significant: t(1136) = 3.62, p = <.01 (two-tailed).

Table 4.10: Generalized Self-Efficacy Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Self-efficacy total	DWC	206	32.57	4.20	.29
	DNWC	932	31.38	4.27	.14

4.3.7 Self-assessed psychological and personal resources – Caregiving experience

Role Captivity Scale

The mean scores range from 0 to 15, with higher scores indicating higher role captivity. The mean score for role captivity among carers was 5.52. Table 4.11 shows rated role captivity between DWC (M=5.45, SD = 2.07) and DNWC (M=5.49, SD = 2.26). Independent samples t-test confirmed that this difference was not significant: t(1140) = -.205, p = >.05.

Table 4.11: Role Captivity Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Role captivity total	DWC	206	5.46	2.07	.14
	DNWC	936	5.49	2.26	.07

Relative Stress Scale

The total scores ranged from 0 to 60, with higher scores indicating more severe stress. The total mean score for relative stress among carers was 19.07. Table 4.12 shows the mean score for relative stress between DWC (M=18.39, SD = 9.48) and DNWC (M=19.11, SD = 9.74). Independent samples t-test indicated the group means were not significantly different: t(1109) = -.950, p = >.05.

Table 4.12: Relative Stress Scale - Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Relative stress total	DWC	200	18.39	9.48	.67
	DNWC	911	19.11	9.74	.32

Positive Aspects of Caregiving Scale

Scores range from 9 (negative perception of caregiving) to 45 (positive perception of caregiving) and questions are individually rated from 1 (disagree a lot) to 5 (Agree a lot). The mean score for positive aspects of caregiving among carers was 28.28. Table 4.13 shows that rating of positive aspects of caregiving between DWC (M=28.60, SD = 7.03) and DNWC (M=28.29, SD = 7.40) was not significantly different; this was confirmed by an Independent samples t-test: t(1141) = .551, p = >.05.

Table 4.13: Positive Aspects of Caregiving Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Positive aspects of caregiving total	DWC	206	28.60	7.03	.49
	DNWC	937	28.29	7.40	.24

Management of Situation Scale

Scores range from 4 (low Management of Situation) to 16 (high Management of Situation). The mean score for Management of Situation among carers was 9.65. Table 4.14 shows that management of situation between DWC (M=9.84, SD = 1.94) and DNWC (M=9.62, SD = 2.00) is not significantly different; this was confirmed by an Independent samples t-test: t(1138) = 1.40, p = >.05.

Table 4.14: Management of Situation Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Management of situation total	DWC	207	9.84	1.94	.13
	DNWC	933	9.62	2.00	.06

Caregiving Competence Scale

The mean total scores range from 1 to 12, with higher scores indicating greater competence. The mean total score for caregiving competence among carers was 9.15. Table 4.15 shows that ratings of caregiving competence are higher among DNWC (M=9.20, SD = 1.66) than DWC (M=8.95, SD = 1.60). This difference was significant; Independent samples t-test: t(1144) = -.1.99, p = <.05 (two-tailed).

Table 4.15: Caregiving Competence Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Caregiving competence total	DWC	208	8.95	1.60	.11
	DNWC	938	9.21	1.66	.05

COPE Index

Using a single item of the COPE Index i.e. ‘Do you feel you cope well as a carer?’ (McKee et al., 2003), total scores range from 1 (Never) to 4 (Always). The total mean score for perceptions of coping among carers was 3.02. Table 4.16 shows that in terms of perceptions of coping, DNWC (M=3.05, SD = .74) rated themselves higher in ability to cope than do DWC (M=2.86, SD = .72). This difference was statistically significant; Independent samples t-test: t(1149) = -3.49, p = <.01 (two-tailed).

Table 4.16: COPE INDEX (single item) – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
COPE INDEX (single item) total	DWC	208	2.86	.72	.05
	DNWC	943	3.05	.74	.02

Modified Social Restriction Scale

I then explored the social restriction scale to assess how easy it is for carers to find someone to look after the PwD if the carer needed respite. The scores range from 1 (the carer can find someone to care for the PwD) to 3 (the carer cannot find someone to care for the PwD). The mean score for social restriction among carers was 3.48. Table 4.17 shows that DWC (M=3.31, SD = 1.32) did not experience as much difficulty as DNWC (M=3.51, SD = 1.35), but the difference marginally failed to reach significance; Independent samples t-test: t(1141) = -1.93, p =.05.

Table 4.17: Modified Social Restriction Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Modified social restriction total	DWC	208	3.31	1.32	.09
	DNWC	935	3.51	1.35	.04

4.3.8 Interim Summary: Care-recipient status, psychological resources, and caregiving experience for the full IDEAL sample

In terms of psychological resources, DWC and DNWC in the full sample demonstrated below mid-range scores of self-esteem and were both much higher in perceptions of self-efficacy and caregiving competence. DWC and DNWC differed on self-efficacy and caregiving competence, with DWC showing a higher degree of self-efficacy than DNWC, and DNWC showing greater confidence in their caregiving competence. Both DWC and DNWC showed low levels of role captivity and relative

stress and were moderately positive towards the caregiving role. DWC and DNWC did not differ on any of these measures. DWC and DNWC also demonstrated above mid-range levels of perceptions of situational management and positive experiences of caregiving and were highly confident in the abilities to cope in the caregiving role. Measures of coping skills between the full sample of DWC and DNWC, differed only on the COPE INDEX (single item), with DNWC reporting greater confidence in their abilities to cope in the caregiving situation than DWC. Finally, while DWC experienced less difficulty finding respite care than DNWC, these differences failed to reach significance.

4.3.9 Self-assessed psychological and personal resources – Social support

Lubben Social Network Scale-6 (Social engagement)

To explore social wellbeing, I looked at 1) Lubben Social Network Scale to assess perceived social support received by family and friends; 2) social relationships subscale from the WHOQOL-BREF. The total Lubben Social Network Scale scores were computed to assess the amount of social support received from family/friends i.e. social engagement, ranging from '0' (no social engagement) to '30' (social engagement with up to 30 relatives/friends). The mean score for social engagement among carers was 17.56. Table 4.18 shows mean total social engagement scores between DWC (M=17.67, SD = 5.41) and DNWC (M=17.53, SD = 5.62). Independent samples t-test confirmed the means were not significantly different between groups: t(1141) = .327, p = >.05.

Table 4.18: Lubben Social Network Scale-6 (Social engagement) - Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Lubben Social Network Scale total	DWC	206	17.67	5.41	.37
	DNWC	937	17.53	5.62	.18

WHOQOL-BREF – Social relationships

The WHOQOL-BREF total scores ranged from ‘2’ very dissatisfied to ‘10’ very satisfied. The mean score for social satisfaction among carers was 7.93. Table 4.19 shows the mean scores for the social relationships domain of the WHOQOL-BREF for DWC (M=7.92, SD = 1.49) than DNWC (M=7.95, SD = 1.37). The scores were not significantly different; Independent samples t-test: t(1151) = -.263, p = >.05). This was true for both personal relationships: t(1154) = 1.21, p = >.05, and support received from friends: t(1157) = -1.65, p = > .05.

Table 4.19: WHOQOL-BREF (social relationships) – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
WHOQOL-BREF (Social relationships) total	DWC	207	7.92	1.49	.10
	DNWC	946	7.95	1.37	.04

4.3.10 Interim Summary: Social support for the full IDEAL sample

While no significant differences were found between DWC and DNWC in terms of social support, both groups experienced difficulty in finding caregiving respite, but had a moderately supportive social network and were highly satisfied with the social support received.

4.3.11 Overall Summary

Overall, carers in this cohort demonstrated mid-range scores in QoL and wellbeing

Psychological resources:

In terms of measures associated with self-assessed psychological wellbeing, carers overall did not demonstrate extreme scores in any of the measures, and in fact,

reported a good level of perceived self-efficacy and caregiving competence. However, self-esteem was lower than average among carers, when compared to population norms.
Caregiving experience:

Most carers reported low levels of role captivity and relative stress. Carers overall did not demonstrate unusually high or low scores in respect of whether they viewed caregiving as a positive experience. The majority of carers were very confident in their abilities to cope with their caregiving responsibilities.

Social support:

Though most carers had difficulty in finding someone to take over care duties, they reported a high level of support from friends and relatives and were satisfied with their support network.

4.3.12 Dementia working carers versus dementia non-working carers

When DWC and DNWC were compared against QoL and wellbeing outcomes, DWC demonstrated a greater overall QoL.

Psychological resources:

DWC reported higher self-efficacy than DNWC.

Caregiving experience:

DNWC felt more competent in the caring role than DWC and had more confidence in their caregiving coping abilities.

Social support:

No significant differences were found between DWC and DNWC in terms of social support.

4.3.13 Interim Summary: Self-assessed psychological and personal resources for the full IDEAL sample

In summarising the findings from this chapter, DWC reported higher self-efficacy, and overall QoL. DNWC, however, were more positive in terms of their competence in the caregiving role and their coping abilities. Importantly, it should be noted that overall differences in total mean scores on most scales were minimal, indicating that despite statistical differences in the outcome of most variables, there was not a substantive difference between most of the group scores.

4.4 Part 3: IDEAL T1 analysis – revised IDEAL working carer sample

As described in part 1 above, there is a considerable difference between the number of DWC versus DNWC, in terms of age and carer-dyad relationship, with a substantially greater number of older, spousal carers in the DNWC group. This may impact statistical comparisons between the groups. To make a correction for this discrepancy in group sizes across ages and carer-dyad relationship, a pseudo-random sample selection procedure was developed to reduce the unequal group sizes. The full sample was organised into 5-year age 'bins', and the spousal carers in the top two years of each 'bin' were excluded from the sample. This left a total of 810 dementia carers (190 DWC and 620 DNWC). The DWC group consisted of 37 males and 153 females, who were spouses (N=57) or family/friend (e.g. adult child/niece or nephew/grand-child/family friend) (N=133). The DNWC group consisted of 197 male carers and 423 female carers, with 519 spousal and 101 non-spousal (i.e. family/friends) carers. To validate the pseudo-random procedure, and to ascertain that it did not substantively affect the means and distributions of the key variables, I reanalysed the key variables already described comparing the sub-sample of DWC and DNWC to the full sample. (NB: differences in N between scales indicates missing data).

Before conducting these analyses, I explored using appropriate independent samples t-test and chi-squared tests (Table 4.20), how the sub-sample of DWC and DNWC differs from the full sample in gender and carer-dyad relationship.

Table 4.20: A comparison of the carer-dyad relationship and gender between the full and revised sub-sample of dementia working carers and dementia non-working carers

Carer-dyad relationship	Working status	Full sample	Sub-sample	Test	P
		N	N		
Spouse	DWC DNWC	954 82 872	576 57 519	$\chi^2 = .73$	.39
Family/friend	DWC DNWC	234 133 101	234 133 101	$\chi^2 = .00$	1.00
Gender					
Male	DWC DNWC	371 45 326	234 37 197	$\chi^2 = 1.66$	.19
Female	DWC DNWC	817 170 647	576 153 423	$\chi^2 = 6.28$	.01

The distribution between spousal DWC and DNWC in the full and revised sample were unequal between groups: χ^2 (1, N = 1998) = .735, p = >.05. However, group differences were equal between the number of female DWC and DNWC in the full and revised sample: χ^2 (1, N = 1998) = 6.28, p = <.05.

4.4.1 Procedure employed for uneven group numbers

Because of substantive differences in the IDEAL dataset in numbers of spousal DWC and DNWC across the different age ranges, statistical analyses and procedures for addressing this discrepancy were discussed with the statistician for the IDEAL Study, but this did not produce a solution. Matching groups using methods such as case control matching (i.e. Field, 2013) could have been used, but this would have discarded more than half of the available data. Therefore, as this study design did not initially set out to balance numbers between working and non-working groups, a procedure was devised to pseudo-randomly remove a percentage of spousal volunteers from each stratified age group without removing representation in each age group. The aim was to effectively redress the balance against the high numbers of non-working spouses in the upper age bracket of the sample. The implemented procedure did not remove the imbalance but reduced it substantially. The procedure is described below. Comparison of the full and revised sample of DWC and DNWC (presented below) confirmed that the mean scores across the key variables were

essentially unchanged in the subgroup. This provides some validation of the pseudo-random procedure designed to deal with the unequal numbers between groups in preparation for the statistical modelling of the data.

The IDEAL database provides the following uneven group numbers when divided by working status:

DWC
Family/friend: 133; spouses: 82

DNWC
Family/friend: 101; spouses: 872

Banding the groups by 5-year age bins, each age band x spousal/nonspousal x working/nonworking category was represented. To reduce numbers of spousal volunteers in the dataset, I removed all spousal volunteers in the first three year groups of each 5-year age bin. Since the majority of spousal carers were in the older age brackets, this differentially reduced the spousal carers in the older age bracket while limiting the loss of spousal carers in the younger age brackets. This is a relatively random way of reducing the numbers of spousal carers in each time bin and reduces the skewed numbers in the upper age bins for the DNWC in the spousal group. The procedure reduced the differential between DWC and DNWC spousal carers, by removing only 25 DWC spousal carers versus 353 DNWC spousal carers.

Result:

DWC
Family/friend: 133; spouses: 57

DNWC
Family/friend: 101; spouses: 519

Descriptives and Table 4.21 below display the distribution in the subsample (parentheses = full sample).

Table 4.21: Breakdown of revised sample by carer-dyad relationship, age group,0 and working status

Working status			Age group													Total
			1	2	3	4	5	6	7	8	9	10	11	12	13	
DWC	**Carer status**	**Spouse**	0	0	0	0 (1)	2 (6)	6 (10)	9 (17)	13 (17)	15 (17)	7 (8)	4 (4)	1 (1)		57
		Family/ friend	2	2	3	19	30	34	35	8	0	0	0	0		133
	Total		2	2	3	19	32	40	44	21	15	7	4	1		190
DNWC	**Carer status**	**Spouse**		0	0	1 (2)	1 (4)	2 (5)	12 (27)	36 (70)	98 (181)	136 (220)	117 (200)	81 (117)	35 (14)	519
		Family/ friend		1	2	3	10	20	12	22	12	8	6	3	2	101
	Total			1	2	4	11	22	24	58	110	144	123	84	37	620
Total	**Carer status**	**Spouse**	0	0	0	1	3	8	21	49	113	143	121	82	35	576
		Family/ friend	2	3	5	22	40	54	47	30	12	8	6	3	2	234
		Total	2	3	5	23	43	62	68	79	125	151	127	85	37	810

4.4.2 Quality of life, wellbeing, and care recipient status for the revised IDEAL sample

EQ-5D – Quality of life

The mean score for QoL among carers was 8.51. The mean total scores for the EQ-5D (Table 4.22) between DWC (M=9.17, SD=1.12) and DNWC (M=8.32, SD=1.52), demonstrated that DWC report a better QoL than DNWC. The independent samples t-test confirmed this was a significant difference between groups: t(793) = 7.04, p = <.01 (two-tailed).

Table 4.22: EQ-5D mean total score – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
EQ-5D Total	DWC	190	9.17	1.12	.08
	DNWC	605	8.32	1.52	.06

WHO-5 Well-Being Index

The mean score for wellbeing among carers was 13.95. Table 4.23 shows mean total wellbeing scores between DWC (M=14.26, SD = 4.60) and DNWC (M=13.91, SD = 4.87). Independent samples t-test indicated the means were not significantly different between groups: t(783) = .856, p = >.05.

Table 4.23: WHO-5 Well-Being Index – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
WHO-5 total	DWC	185	14.26	4.60	.33
	DNWC	600	13.91	4.87	.19

Care recipient status

Dependence Scale

The total carer-rated assessment score of PwD dependence was 5.65. Table 4.24 shows the dependence needs of PwD between DWC (M=5.66, SD = 2.48) and DNWC (M=5.66, SD = 2.65). Independent samples t-test confirmed the means were not significantly different: t(752) = -.009, p = >.05.

Table 4.24: Dependence Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Dependence total	DWC	175	5.66	2.48	.18
	DNWC	579	5.66	2.65	.11

4.4.3 Interim Summary: Quality of life, wellbeing, and care recipient dependence for the revised IDEAL sample

As with the full sample, QoL and wellbeing scores between the revised sample of DWC and DNWC are above mid-range and demonstrate a difference between DWC and DNWC in their QoL scores only, with DWC reporting a higher QoL. Level of dependence of their relative did not differ between groups.

4.4.4 Self-assessed psychological and personal resources – Psychological resources for the revised IDEAL sample

Self-esteem: Rosenberg Self-Esteem scale (reversed)

The total mean score for self-esteem among carers was 21.17. Table 4.25 shows self-esteem between DWC (M=21.43, SD = 4.73) and DNWC (M=21.10, SD = 4.51). Independent samples t-test confirmed this was not significantly different between groups: t(769) = 867, p = >.05.

Table 4.25: Rosenberg Self-Esteem Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Self-esteem total	DWC	181	21.43	4.73	.35
	DNWC	590	21.10	4.51	.18

Generalized Self-Efficacy Scale

The total mean score for perceived self-efficacy among carers was 31.72. Table 4.26 shows that self-efficacy is higher among DWC (M=32.71, SD = 4.29) than DNWC (M=31.31, SD = 4.25). This difference was significant; Independent samples t-test: t(769) = 3.59, p = <.01 (two-tailed).

Table 4.26: Generalized Self-Efficacy Scale – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
Self-efficacy total	DWC	182	32.71	4.29	.31
	DNWC	589	31.41	4.25	.17

4.4.5 Interim Summary: Psychological and personal resources for the revised IDEAL sample

As with the full sample of DWC and DNWC, psychological resources in the revised sample demonstrated below mid-range scores of self-esteem, but both groups scored higher in perceptions of self-efficacy. DWC and DNWC differed on self-efficacy only, with DWC reporting higher self-efficacy than DNWC.

4.4.6 Self-assessed psychological and personal resources - Caregiving experience for the revised IDEAL sample

Role Captivity Scale

The mean score for role captivity among carers was 5.54. Table 4.27 shows rated role captivity between DWC (M=5.46, SD = 2.07) and DNWC (M=5.53, SD = 2.27) Independent samples t-test confirmed this difference was not significantly different: t(772) = -.338, p = >.05.

Table 4.27: Role Captivity Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Role captivity total	DWC	182	5.46	2.07	.15
	DNWC	592	5.53	2.27	.09

Relative Stress Scale

The total mean score for relative stress among carers was 18.90. Table 4.28 shows the mean score for relative stress between DWC (M=18.30, SD = 9.27) and DNWC (M=18.90, SD = 9.66). Independent samples t-test confirmed the means were not significantly different: t(749) = -.721, p = >.05.

Table 4.28: Relative Stress Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Relative stress total	DWC	176	18.30	9.27	.69
	DNWC	575	18.89	9.66	.40

Positive Aspects of Caregiving Scale

The mean score for positive aspects of caregiving among carers was 28.43. Table 4.29 shows ratings of positive aspects of caregiving between DWC (M=29.08, SD = 6.97) and DNWC (M=28.31, SD = 7.57). Independent samples t-test confirmed the means were not significantly different: t(774) = 1.21, p = >.05.

Table 4.29: Positive Aspects of Caregiving Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Positive aspects of caregiving total	DWC	182	29.08	6.67	.51
	DNWC	594	28.31	7.57	.31

Management of Situation Scale

The mean score for Management of Situation among carers was 9.67. Table 4.30 shows mean scores for management of situation between DWC (M=9.95, SD = 1.90) and DNWC (M=9.59, SD = 1.94). Independent samples t-test indicated these were significantly different: t(774) = 2.15, p = <.05 (two-tailed).

Table 4.30: Management of Situation Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Management of situation total	DWC	183	9.95	1.90	.14
	DNWC	593	9.59	1.94	.08

Caregiving Competence Scale

The mean total score for caregiving competence among carers was 9.17. Table 4.31 shows that rating of caregiving competence was higher among DNWC (M=9.24, SD = 1.63) than DWC (M=8.97, SD = 1.65). This difference was not statistically significant; Independent samples t-test: t(777) = -.1.93, p = >.05.

Table 4.31: Caregiving Competence Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Caregiving competence total	DWC	184	8.97	1.51	.11
	DNWC	595	9.24	1.63	.06

COPE Index

The total mean score for perceptions of coping among carers was 3.01. Table 4.32 shows that DNWC (M=3.06, SD = .74) rate themselves higher in ability to cope than do DWC (M=2.84, SD = .71). This difference was statistically significant; Independent samples t-test: t(779) = -3.55, p = <.01 (two-tailed).

Table 4.32: COPE INDEX (single item) – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
COPE Index (single item) total	DWC	184	2.84	.71	.05
	DNWC	597	3.06	.74	.03

Modified Social Restriction Scale

The mean score for social restriction among carers was 3.50. Table 4.33 shows that DWC (M=3.29, SD = 1.33) have less difficulty than DNWC (M=3.56, SD = 1.39) when finding someone to care for the PwD; Independent samples t-test: t(775) = -2.31, p = <.05 (two-tailed).

Table 4.33: Modified Social Restriction Scale – Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Modified Social Restriction total	DWC	184	3.29	1.33	.09
	DNWC	593	3.56	1.39	.05

4.4.7 Interim Summary: Caregiving experience for the revised IDEAL sample

Like the full sample, both DWC and DNWC experienced mid-range scores in role captivity, low levels of stress, and above mid-range levels of positive perceptions of caregiving. No significant differences were obtained between groups in their experiences of role captivity, relative stress or positive caregiving experiences.

Similarly to the full sample of DWC and DNWC, both groups in the revised sample scored higher in perceptions of caregiving competence. Like the full sample, DWC and DNWC in the sub-sample were both much higher in perceptions of caregiving competence. However, unlike DWC and DNWC in the full sample, carers in the revised sample did not differ on caregiving competence. As with the full sample of DWC and DNWC, both DWC and DNWC in the revised sample demonstrated above mid-range levels of perceptions of situational management. Unlike the full sample however, DWC and DWC in the revised sample demonstrated significant differences in their perception of situational management, with DWC demonstrating greater confidence in their ability to manage situations than DNWC.

In line with the findings from the full sample, both DWC and DNWC in the revised sample were also highly confident in their abilities to cope in the caregiving role. As found in the full sample, assessments of caregiver copingbetween the revised sample

of DWC and DNWC carers differed between groups, with DNWC showing greater confidence in their abilities to cope in the caregiving situation than DWC. Marginal differences emerged between the sub- and the full sample in their ability to obtain caregiving respite, with DNWC experiencing more difficulty than DWC in the revised sample (full sample means marginally failed to reach statistical significance).

4.4.8 Self-assessed psychological and personal resources - Social support for the revised IDEAL sample

Lubben Social Network Scale-6 (Social engagement)

The mean score for social satisfaction among carers was 17.41. Table 4.34 shows mean total social engagement scores between DWC (M=17.64, SD = 5.51) and DNWC (M=17.30, SD = 5.72). Independent samples t-test confirmed the means were not significantly different between groups: t(772) = .704, p = >.05.

Table 4.34: Lubben Social Network Scale-6 (Social engagement) - Dementia working carers versus dementia non-working carers

	Working status	**N**	**Mean**	**Std. Deviation**	**Std. Error Mean**
Lubben Social Network total	DWC	181	17.64	5.51	.41
	DNWC	593	17.30	5.72	.23

WHOQOL-BREF (Social relationships)

The mean score for social relationships among carers was 7.92. Table 4.35 shows the mean scores for the social relationships domain of the WHOQOL-BREF was not significantly different; Independent samples t-test: t(1151) = -.263, p = >.05 for DWC (M=7.99, SD = 1.46) than DNWC (M=7.92, SD = 1.41). This was true for support received from friends: t(787) = -1.11, p = > .05, but not for satisfaction with personal relationships: t(784) = 2.0, p = < .05 (two-tailed), which was higher among DWC (M=4.19, SD=.83) than DNWC (M=4.04, SD =.85) .

Table 4.35: WHOQOL-BREF (social relationships) – Dementia working carers versus dementia non-working carers

	Working status	N	Mean	Std. Deviation	Std. Error Mean
WHOQOL-BREF (Social relationships) total	DWC	183	7.99	1.46	.10
	DNWC	601	7.92	1.41	.05

4.4.9 Interim Summary: Social support for the revised IDEAL sample

As with the full group of DWC and DNWC, no significant differences were found between DWC and DNWC in terms of employed social support, and both groups had trouble in finding caregiving respite, but had a moderately supportive social network and were highly satisfied with the social support received. DWC were also more highly satisfied with their personal relationships than DNWC.

4.5 Overall summary

The above findings have shown that the demographic profile of the whole sample is centred on DWC and DNWC who care for individuals predominantly with Alzheimer's disease, with most carers being female. The demographic profile was somewhat different between DWC and DNWC, with a greater number of DNWC in the older age groups and consisting of spousal carers. DWC however, have an almost equal chance of being a spouse or a family/friend of the PwD, and are more likely to be providing less than 10 hours of daily care. When QoL and wellbeing were compared between groups, DWC reported higher QoL scores than DNWC, and a higher degree of self-efficacy than DNWC. DNWC however, have greater confidence in their competence in the caregiving role.

Comparisons between the full sample and revised sample in the IDEAL cohort, found that DWC reported greater QoL than DNWC, while DNWC reported greater confidence in their abilities to cope in the caregiving situation. However, unlike DWC and DNWC in the full sample, DWC and DNWC in the revised sample did not differ on caregiving competence. Furthermore, DWC in the revised sample demonstrated greater confidence in their ability to manage situations. DNWC also experienced more difficulty

than DWC in the revised sample to obtain caregiving respite, though the means marginally failed to reach significance. Comparison of the full and revised sample of DWC and DNWC therefore, confirmed that the mean scores across the key variables were essentially unchanged in the subgroup. This validates the pseudo-random procedure designed to deal with the unequal numbers between groups in preparation for the statistical modelling of the data.

Chapter 5:

Quality of life and wellbeing of dementia carers: are there differences between working dementia carers and dementia non-working carers?

Note: *This chapter was written and submitted for journal publication, and it is presented as a journal paper here. As result, there is some repetition from other parts of the thesis.*

5.1 Introduction

In the UK, an estimated 670,000 people act as primary carers for people with dementia (PwD), therefore it is unsurprising that the National Dementia Strategy England identifies that dementia carers are one of the most important resources for PwD (DoHb, 2009).

The current Care Act (Legislation.gov.uk, 2014), seeks to strengthen the recognition and rights of carers and care recipients, by defining the importance of carer wellbeing, and placing a duty on local authorities to identify carers with unmet needs (Assessments and the Care Act, 2015). For family carers of PwD, providing care can be a challenging task, being described as more strenuous than caring for a person with a chronic disease (Brodaty & Donkin, 2009). Many studies have explored the factors that impact the quality of life (QoL) and wellbeing of dementia carers[3]. The (more typical) older adult family carers that care for PwD report high levels of depression and physical illness, and a diminished QoL (Schulz & Sherwood, 2008; Schölzel-Dorenbos et al., 2009 – measured by the Schedule for the Evaluation of Individual Quality of Life; Fonareva & Oken, 2014), which can be exacerbated by disruptive behaviours (i.e. agitation, aggression, disinhibition) of PwD (Cheng, 2017). Care-recipient behaviours and caregiving competence are also found to be essential features of resilience, whilst the quality of the carer-dyad relationship and social support were also emphasised (Norton et al., 2009; Walters et al., 2010; LaFontaine & Oyebode, 2013; Rattinger et al., 2016; Joling et al., 2017). Other research with dementia carers (Bristow et al., 2008; Brodaty &

[3]Whilst there is overlap and nuanced differences between QoL and wellbeing, these are commonly used interchangeably: both include both positive and negative feelings, personal wellbeing, health status; physical functioning; psychosocial adjustment; satisfaction with life; and happiness (Schalock, 2004; Ferrans et al., 2005; Diener, 2006; Camfield & Skevington, 2008).

Donkin, 2009) has similarly highlighted the necessity of social support from the immediate family and from professional supporting services, for the maintenance of wellbeing, providing a buffer against burden and stress by increasing their perception that resources are available to handle stress.

In Pearlin and colleagues' (1990) Stress Process model (SPM), stressors, such as the level of dependency of the PwD, perceived work-life conflict and role captivity, predict poorer wellbeing for dementia family carers. According to the SPM, the mediating factors that can reduce the impact of stressors include positive coping mechanisms and practical and emotional social support from others. Positive coping mechanisms i.e. reappraisal strategies and active problem-solving, have been reported to correlate with reduced burden, wishful thinking and lower rates of depression (Papastavrou et al., 2011), higher levels of mental and physical health, life satisfaction, and positive gains such as caregiving rewards (Braun et al, 2009). In a recent systematic review, carers' physical and mental health, independence, and respite activities were associated with better carer QoL outcomes (Farina et al., 2017). However, a greater need for research into understanding the factors that are associated with carer QoL was identified.

In the UK alone, an estimated 2.6 million people combine paid work and caring (The Work Foundation, 2017), and an estimated 270,000 carers in the UK combining dementia care with a working role (Doewick & Southern, 2014). Across several European states, work-family reconciliation is recognised as an independent right (Masselot & Caracciolo di Torella, 2010). In the UK, the Carers Strategy is embedded in the government's general principle, that paid work is vital for ensuring financial independence, preventing social exclusion, and enriching personal wellbeing (Hillage & Pollard, 1998). This additional role is likely to add to the demands of dementia care. Indeed, among carers over 45 who balance a working role with caregiving for elderly relatives, there is an increased likelihood that carers will report depressive symptoms (Dugan et al., 2016). Employment has also been associated with positive wellbeing outcomes for carers, however, serving as a respite from the responsibilities of care, and protecting against the detrimental effects of caregiving stress (Healthways & Coughlin, 2010; Newbronner et al., 2013). Furthermore, working while providing care increases personal satisfaction from work-based achievements, and increases the likelihood for greater social integration and participation in activities of interest (Utz et al., 2011), and increased financial resources (Healthways & Coughlin, 2010). In Asia, Nurfatihah et al.

(2013) and Wang et al. (2013) reported that combined employment and care roles were associated with lower QoL, and wellbeing, indexed by emotional, physical and general health, and social functioning. In a review of role-conflict literature, Sharma and colleagues (2016), reported that female carers experienced greater role-strain and role-conflict than male carers. Braun and colleagues (2009) have also found that males seemed to adapt better to the caregiving role than females. Greater role-strain in women produced more frequent health problems, a less positive outlook on life, and a greater need for external support. This is based on the multiple roles women play, as wives, daughters, mothers, and/or employees, plus greater hours spent on caregiving (Calasanti & Bowen, 2006). Other studies, however, have not found a gender difference (i.e. Russell, 2001; Prince, 2004; Baker & Robertson, 2008). Research with dementia working carers (DWC) in the UK is more limited, but Newbronner et al (2013) reported that caregiving impacted on dementia carers' ability to obtain or remain in employment.

In this chapter, I analyse secondary data from the IDEAL Study to explore how QoL and wellbeing among DWC and dementia non-working carers (DNWC) is impacted by an individuals' personal and psychological resources. While the WHO-5 Well-Being Index was selected to explore wellbeing, the choice across the diverse measures of QOL is more complex. QoL measures can be more generic (i.e. used across all disorders and health states) or disease/condition specific (i.e. relating to a single disorder or health state). As generic measures of QoL (e.g. SF-36, EQ-5D) are the most commonly used option to assess QoL in dementia carers (Farina et al., 2017), I elected to use as my primary QoL index a measure which incorporates both physical and mental health, specifically the EQ-5D. The EQ-5D is conventionally considered a health-related QoL index, as distinct from QoL measures that address various domains of life, including: economic, psychological, and physical wellbeing; social relations; social, community and civic activities; personal development, fulfilment, and recreation; level of independence; spirituality, religion and personal beliefs (WHOQOL Group, 1998; Burckhardt & Anderson, 2003). As demonstrated by previous research (i.e. Nurfatihah et al., 2013; Fonareva & Oken, 2014; Ervin et al., 2015; Raivio et al., 2015) however, instruments selected to measure QoL are often nonuniform (i.e. Depression Anxiety Stress Scales (DASS); Schedule for the Evaluation of Individual Quality of Life; Psychological Well-Being Scale; Short-Form Health Survey). Schrag and colleagues (2000) also referred to the EQ-5D as a generic QoL instrument which has been extensively validated and is sensitive, internally consistent, and reliable in the general population and other patient

groups.

In the IDEAL Study, carer self-reports of QoL were limited to the WHOQOL-BREF and the EQ-5D. While the WHOQOL-BREF independently explores various QoL sub-domains (i.e. physical health, psychological health, social relationships, and environment) and two general items which measure overall QoL and general health, it does not provide an overall composite score. Therefore, the EQ-5D was considered the most appropriate measure of QoL. In this chapter I explore the following questions:

1. Is the experience of QoL and wellbeing different for DWC and DNWC?
2. What psychological, caregiving experience and social support resources most impact QoL and wellbeing among DWC and DNWC?

5.2 Method

Sample

Participants were recruited to the IDEAL study, under the protocol reported elsewhere (Clare et al., 2014). The study comprised 1283 primary dementia family carers. The majority of carers in this sample were caring for persons who had been diagnosed with Alzheimer's disease (N=715), with 45 individuals diagnosed with frontotemporal dementia (FTD), 142 with Vascular dementia, 263 with mixed dementia, 43 with Parkinson's disease dementia, 43 with Lewy Body dementia, 27 with unspecified dementia, and 5 with 'other' dementia. I excluded the 45 carers who provide care for people with FTD based on the pronounced behavioural differences in this diagnosis, and the increased likelihood of early onset dementia which could bias the findings (Nicolaou et al., 2010). An additional 45 carers were excluded from analysis due to ambiguity in employment status, leaving data was available for 215 DWC and 973 DNWC. Mean age for DNWC was 72.3 years (range 71 to 76), and for DWC was 55.5 years (range 56 to 60). There were 872 spousal DNWC, and 82 spousal DWC, 101 non-spousal DNWC, and 133 non-spousal DWC. A pseudo-random sample selection procedure was developed to reduce the unequal group sizes and so that DWC and DNWC were age-matched as follows. The full sample was organised into 5-year age categories, and spousal carers in the top two years of each 'bin' were excluded from the sample up to the age of 88. This left a total of 810 dementia carers (190 DWC and 620 DNWC). The DWC group consisted

of 37 males and 153 females, 57 spouses, and 133 family/friends (e.g. adult child/grand-child/friends) (N=133). The DNWC group consisted of 197 male carers and 423 female carers, 519 spousal and 101 non-spousal carers.

Research instruments

I extracted data from instruments used in the IDEAL study which, following the factors established in the parent paper from the IDEAL (Clare et al., 2014), were grouped as follows:

1. Outcome measures: QoL - EQ-5D; Wellbeing - WHO-5 Well-Being Index.
2. Covariate measures: Dependence Scale; age, gender, carer-dyad relationship.
3. Psychological resources: Rosenberg Self-Esteem Scale; Generalized Self-Efficacy Scale;
4. Caregiving experience: Role captivity Scale; Relative Stress Scale; Positive Aspects of Caregiving Scale, Management of Situation Scale; Caregiving Competence Scale; COPE INDEX (single item); Modified Social Restriction Scale;
5. Social support: Lubben Social Network Scale-6; selected questions from the WHOL-BREF social relationships sub-domain.

5.3 Analysis

Preliminary analyses established the comparability of a) the full sample and the subsample, and b) the subsample DNWC and DWC groups on outcome and covariate indices. For categorical data, Pearson's Chi-Square was used. For continuous data, student's t-test was used. Effect sizes and p values are reported for each comparison.

Using the subsample, a MANCOVA was run with WHO-5 and EQ-5D as the dependent variables, controlling for covariates (age, gender, carer-dyad relationship and dependence), to determine whether working status significantly predicted variance of QoL outcomes. Through adopting a MANCOVA initially I was able to assess patterns between the two dependent variables, which is particularly important when considering the extent to which the selected measures (traditionally reflecting QoL and wellbeing respectively) overlap. In a MANCOVA, multiple dependent variables for differences between independent groups can be examined, while controlling for other variables

(categorical or continuous) that may also be related to the dependent variable (Taylor, 2010). The MANCOVA was selected on the assumption that the observations were independent of one another, there was not any pattern for the selection of the sample, and the sample represented a random population (Statistics Solutions, 2018). Subsequently, a series of univariate multiple regression models were created to identify the variance accounted for by working status on each outcome. In Model A, the dependent variable was the EQ-5D. In the first block confounding variables (age, gender, carer-dyad relationship, and dependence) were entered as covariates. In the second block the working status was entered in the model. Finally, all independent variables (i.e. Relative Stress; Self-esteem; Management of Situation; Role Captivity; Positive Aspects of Caregiving; Caregiver Coping; Caregiving Competence; Social network; Social restriction; Social relationships) were entered, and variables that significantly contributed variance were retained in the model. Entering these variables last, demonstrated how much additional variance they contribute on top of the working status and covariates. Model B used the same process with WHO-5 as the dependent variable.

Bivariate correlations (see Appendix XXVI) indicated that all instruments were significantly correlated apart from the Positive Aspects of Caregiving Scale and the Management of Situation Scale, and the Self-Efficacy Scale and the Management of Situation Scale.

5.4 Results

Table 5.1 provides descriptive data (e.g. means, standard deviations, frequency) for covariate and outcome measures in both the full IDEAL sample and the subsample. Table 5.2 provides descriptive data for the subsample, stratified by working status.

The full IDEAL sample (n = 1238) and the subsample used in this study (n=845) differed in age and the carer-dyad relationship only (all ps<.001). Dementia carers in the full sample were older (M=69.31 versus M=67.57). There was a higher proportion of spousal carers in the full sample (80.5% versus 71.5%). The subsample did not differ from the whole sample in subjective estimates of QoL or wellbeing (ps>.05).

In the subsample, DNWC were significantly older than DWC: t(808) = -21.27, = p <.001. There were a greater proportion of females: χ^2 (1, N = 810) = 10.71, p = <.01 and a greater proportion of non-spousal carers: χ^2 (1, N = 810) = 204.21, p = <.001; in the DWC group. The DWC group had significantly higher scores on the EQ-5D compared to the

DNWC: t(793) = 7.04, p = <.001 (two-tailed); there was no significant difference between scores on the WHO-5: t(783) = .856, p = >.05.

Table 5.1: A comparison of covariates and outcome measures between the full and revised sub-sample of dementia carers

	Full sample			Sub-sample				
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**Test**	**P**
Gender **Male** **Female**	1237 387 850			845 245 600			$\chi^2 = 1.24$	.26
Age	1236	69.31	11.09	844	67.57	11.65	t = 3.42	p<.001
Carer-dyad relationship **Spouse** **Non-spousal**	1238 996 242		.	845 604 241			$\chi^2 = 22.70$	p<.001
Dependence Scale	1155	5.64	2.61	782	5.65	2.62	t = -.79	.91
EQ-5D (NB: Higher scores represent better QoL)	1206	8.46	1.55	827	8.51	1.50	t = -.79	.42
WHO-5	1203	13.83	4.92	819	13.95	4.86	t = -.53	0.59

Table 5.2: A comparison of covariates and outcome measures between dementia working carers and dementia non-working carers (revised sample)

	DWC			DNWC				
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**Test**	**P**
Gender **Male** **Female**	190 37 153			620 197 423			$\chi^2 = 10.71$	.001
Age	190	54.98	9.08	620	71.46	9.41	t = -21.27	p<.001
Carer-dyad relationship **Spouse** **Non-spousal**	190 57 133		.	620 133 101			$\chi^2 = 204.21$	p<.001
Dependence Scale	175	5.66	2.48	579	5.66	2.65	t = -.00	.99
EQ-5D (NB: Higher scores represent better QoL)	190	9.17	1.12	605	8.32	1.52	t = 7.04	p<.001
WHO-5	183	14.26	4.60	600	13.91	4.87	t = .85	0.39

The initial MANCOVA (see Appendix XXVII) revealed a statistically significant difference between the DWC and DNWC groups on the combined QoL variables (EQ-5D and WHO-5) after controlling for covariates: F (2, 729) = 9.72, p = <.001, Wilks' Λ=.97, partial η^2 =.97.

5.4.1 Multiple Regression Models

I performed two multiple regression models to identify the variance accounted for by working status on EQ-5D (Model A, Table 5.3) and WHO-5 (Model B, Table 5.4) outcomes independently with the revised sample (N=810). In both models, working status was entered in the second step of the model after controlling for potential confounding variables (age, gender, carer-dyad relationship, and dependence).

Table 5.3: Model A. Dependent variable EQ5D (total score, reversed scored)

Model output	Final model variables						
	Unstandardised B	**Standardised Beta**	**P**	**Adjusted R**	**Delta r (Score difference between steps)**	**F**	**P**
Step 1				.07		14.32	p<.001
Age	-.01	-.14	p<.01				
Gender: Male	.52	.16	p<.001				
Carer dyad-relationship: Family/friend	-.45	-.14	p<.01				
Dependence	-.03	-.05	.13				
Step 2				.09	.02	14.52	p<.001
Age	-.00	-.05	.32				
Gender: Male	.52	.16	p<.001				
Carer dyad-relationship: Family/friend	-.35	-.10	.04				
Dependence	-.02	-.04	.25				
Working status: DWC	-.61	-.17	p<.001				
Step 3				.23	.14	33.76	p<.001
Age	-.01	-.09	.08				
Gender: Male	.31	.09	p<.01				
Carer dyad-relationship: Family/friend	-.31	-.09	.04				
Dependence	-.00	-.47	.63				

Working status: DWC	-.48	-.14	p<.01				
Self-esteem	.12	.37	p<.001				
Step 4				.25	.02	33.73	p<.001
Age	-.01	-.10	.04				
Gender: Male	.23	.07	.04				
Carer dyad-relationship: Family/friend	-.24	-.07	.11				
Dependence	.04	.07	.04				
Working status: DWC	-.46	-.13	p<.01				
Self-esteem	.09	.30	p<.001				
Relative stress	-.03	-.21	p<.001				

a The model excluded the following variables: Generalised Self-efficacy Scale; Management of Situation; Positive Aspects of Caregiving; The COPE Index (single item); Caregiving Competence Scale; Lubben Social Network Scale-6; Role-Captivity Scale; Modified Social Restriction Scale; WHOQOL-BREF – Social relationships.

Table 5.4: Model B. Dependent variable WHO-5

Model output	Final model variables						
	Unstandardised B	**Standardised Beta**	**P**	**Adjusted R**	**Delta r (Difference in scores)**	**F**	**P**
Step 1				.11		22.25	p<.001
Age	.02	.06	.21				
Gender: Male	2.55	.24	p<.001				
Carer dyad-relationship: Family/friend	-1.28	-.12	.01				
Dependence	-.40	-.22	p<.001				
Step 2				.11	.00	18.32	p<.001
Age	.04	.10	.07				
Gender: Male	2.55	.24	p<.001				
Carer dyad-relationship: Family/friend	-1.15	-.11	.03				
Dependence	-.39	-.21	p<.001				
Working status: DWC	-.80	-.07	.12				
Step 3				.34	.23	59.90	p<.001
Age	.02	.05	.30				
Gender: Male	1.50	.14	p<.001				
Carer dyad-relationship: Family/friend	-.52	-.05	.26				
Dependence	.08	.04	.21				
Working status: DWC	-.45	-.04	.30				

Step 4				.43	.09	75.59	p<.001
Age	.01	.03	.45				
Gender: Male	1.19	.11	p<.001				
Carer dyad-relationship: Family/friend	-.60	-.05	.16				
Dependence	.00	.00	.96				
Working status: DWC	-.17	-.01	.67				
Relative stress	-.20	-.41	p<.001				
Self-esteem	.35	.33	p<.001				
Step 5				.47	.04	76.76	p<.001
Age	.00	.01	.79				
Gender: Male	1.39	.13	p<.001				
Carer dyad-relationship: Family/friend	-.35	-.03	.39				
Dependence	-.01	-.01	.75				
Working status: DWC	-.16	-.01	.68				
Relative stress	-.16	-.33	p<.001				
Self esteem	.29	.28	p<.001				
Social relationships	.72	.22	p<.001				
Step 6				.48	.01	70.32	p<.001
Age	.01	.02	.54				
Gender: Male	1.28	.12	p<.001				
Carer dyad-relationship: Family/friend	-.43	-.04	.30				
Dependence	-.02	-.01	.63				

Working status: DWC	-.07	-.00	.84				
Relative stress	-.16	-.33	p<.001				
Self esteem	.24	.23	p<.001				
Social relationships	.69	.21	p<.001				
Self-efficacy	.11	.10	p<.01				
Step 7				.48	.00	64.18	p<.001
Age	.01	.02	.54				
Gender:1 Male	1.33	.12	p<.001				
Carer dyad-relationship: Family/friend	-.47	-.04	.25				
Dependence	-.02	-.01	.72				
Working status: DWC	-.05	-.00	.88				
Relative stress	-.16	-.33	p<.001				
Self esteem	.24	.23	p<.001				
Social relationships	.59	.18	p<.001				
Self-efficacy	.11	.10	p<.01				
Social network	.05	.06	.02				
Step 8				.49	.01	59.19	p<.001
Age	.01	.02	.54				
Gender: Male	1.25	.12	p<.001				
Carer dyad-relationship: Family/friend	-.47	-.04	.25				
Dependence	-.03	-.01	.55				
Working status: DWC	-.02	-.00	.95				
Relative stress	-.15	-.32	p<.001				

Self esteem	.24	.23	p<.001				
Social relationships	.56	.17	p<.001				
Self-efficacy	.11	.10	p<.01				
Social network	.06	.07	.02				
Positive aspects of caregiving	.04	.06	.02				
Step 9				.49	.00	55.24	p<.001
Age	.01	.02	.52				
Gender: Male	1.25	.12	p<.001				
Carer dyad-relationship: Family/friend	-.54	-.05	.18				
Dependence	-.04	-.02	.50				
Working status: DWC	-.01	-.00	.97				
Relative stress	-.16	-.34	p<.001				
Self esteem	.23	.23	p<.001				
Social relationships	.58	.17	p<.001				
Self-efficacy	.11	.10	p<.01				
Social network	.07	.09	p<.01				
Positive aspects of caregiving	.05	.07	p<.01				
Modified Social Restriction	.27	.07	.01				

*The model excluded the following variables: Management of Situation; The COPE Index (single item); Caregiving Competence Scale; The Role Captivity Scale.

5.4.2 Contribution of working status to quality of life

In Model A (EQ-5D), working status accounted for an additional 2% of the variance; whilst in Model B (WHO-5), working status accounted for 0% of the variance. In both models, DNWC was associated with poorer QoL scores, though this was only statistically significant in Model A (EQ-5D) (β= -0.62, p = <.001).

5.4.3 Contribution of psychological and caregiver experience variables

In Model A, two additional variables were retained following step-wise additions into the model (step 3): self-esteem and relative stress. These two variables accounted for 16% of the final model, with higher self-esteem and reduced relative stress associated with better EQ-5D scores. The final model accounted for 26% variance, and significantly predicted EQ-5D scores (F=33.73, p = <.001). Within the final model, younger, male, DWC with greater care-recipient dependence experienced better EQ-5D scores.

In Model B, seven additional variables were retained following step-wise additions into the model (step 3): self-esteem, self-efficacy, positive aspects of caregiving, relative stress, social relationships, social network, and modified social restriction. These seven variables accounted for an additional 38% of the variance of the final model. The final model accounted for 49% of the variance, and significantly predicted WHO-5 scores (F=55.24, p = <.001). The direction of associations indicated that males experienced higher wellbeing scores. Within the final model, better WHO-5 scores were also associated with being male, having greater self-esteem, better self- efficacy, a more positive view of the caregiving role, reduced relative stress, more satisfaction with social relationships, a larger social network, but also more social restriction. Importantly, working status was not significantly associated with WHO-5 scores in the final model.

5.5 Discussion

The primary aim of this chapter was to explore potential differences on reported QoL and wellbeing measures between DWC and DNWC. Broadly, the findings highlighted that working status contributed significantly to carer QoL, measured by EQ-5D indices. These findings support previous research (Healthways & Coughlin, 2010;

Newbronner et al., 2013) which suggests that employment is associated with positive outcomes for carers, by potentially serving as a respite from the responsibilities of care and protecting against the detrimental effects of caregiving stress. There are two important caveats in this data. First, although working status did add to the EQ-5D model, it only contributed 2% of the variance; and second, working status did not significantly predict higher WHO-5 scores. Whilst unexpected, the findings can be attributed to the fact that the EQ-5D is also defined as a measure of health-related quality of life (HRQoL) and the WHO-5 is defined as a measure of wellbeing, capturing different underlying constructs (EQ-5D = mobility, self-care, usual activities, pain/discomfort, anxiety/depression; WHO-5 = positive mood, vitality, and general interests). In comparison to other methods of measuring overall QoL (i.e. WHOQOL Group, 1998), the EQ-5D is not ideal, though it is to date one of the most commonly used measures of QoL and provides a composite measure which incorporates both physical health and mental health indices. As Camfield and Skevington (2008) highlighted, the concepts of QoL and wellbeing are often used interchangeably. Other researchers (Tyack & Camic, 2017) have similarly stated that QoL is "synonymous with subjective wellbeing" (p. 1262), as the "intrinsic felt experience of individuals" (Cunningham et al., 2018, p. 9). In fact, the WHO-5 and EQ-5D significantly correlated between all domains of each measure (Janssen et al., 2013). Furthermore, Skevington and Böhnke (2018), argue for the potential to integrate measures of subjective wellbeing and QoL, to achieve more validity for holistic measures of subjective health than either model alone. However, other definitions of QoL hold that it is a broader ranging concept which is impacted by physical and psychological health, personal convictions, relationships with others, and the surrounding environment (WHO, 2018). Recent research findings provide a rationale for the inclusion of even more domains (i.e. change in the PwD, acceptance of the caring role, evaluation of support, weight of responsibility, and role conflict), which are unrepresented in generic QoL models (Daley et al., 2018).

The findings of this chapter suggest that QoL is arguably a more subjective and multidimensional measure and that the specific tool selected is a critical determinant of the extent to which QoL and wellbeing outcomes measure overlapping concepts. The findings argue that the interchangeability between the EQ-5D health-related indices of QoL and the WHO-5 wellbeing measures should be re-evaluated, since working status conferred benefits to EQ-5D QoL but not to WHO-5 wellbeing. As Camfield and Skevington (2008) conclude, without definitional and conceptual agreement, it is not yet

possible to determine what the universal relationship between QoL and subjective wellbeing really is.

In this selective comparison of a subpopulation of DWC and DNWC from the IDEAL cohort, independent of working status, higher self-esteem and reduced relative stress were the only two common contributors to both models. Other research has similarly found an association between self-esteem and indices of QoL and wellbeing (Robinson, 1990; Brodaty & Donkin, 2009). Previous research on dementia family carers has also found a significant association between stress with QoL (as measured by two general items on the WHOQOL-BREF (Häusler et al., 2016) and broad domains of emotional, psychological and physical wellbeing (as measured by the Depression Anxiety Stress Scales (DASS) (Ervin et al., 2015); the Short-Form Health Survey (Fauth et al., 2015); the Psychological Well-Being Scale (Raivio et al., 2015)). Interestingly, the particular psychological, caregiving experiences, and supportive resources explored here provided a better overall model for the WHO-5 wellbeing outcome than for the EQ-5D QoL outcome measures. Specifically, self-efficacy and positive perceptions of caregiving additionally contributed to the model for increased wellbeing. These contributions were not impacted differentially by working status.

An unexpected finding was the association of greater social restriction (i.e. difficulty finding someone to care for the PwD) with higher wellbeing. In considering the mediating effects of caregiving stress however, Pearlin et al. (1990) proposed that social support and positive coping strategies impact positively on wellbeing. In the present study, regardless of employment status, higher wellbeing was reported by DWC who employed social support from friends and family. It is surprising that this association was not specific to the working status of the carer, given that the DWC might be expected to make a greater call on support systems. Bristow et al. (2008) and Brodaty and Donkin (2009) have similarly found that both emotional and instrumental support were essential for sustaining psychological wellbeing in dementia carers. In the wellbeing model, independent of working status again, good social relationships and social networks were indeed predictors of higher wellbeing.

Self-efficacy and positive aspects of caregiving were significant contributors to the final wellbeing model, and impact both DWC and DNWC. Self-efficacy has a strong, negative relationship with depressed symptoms for dementia family carers (Gilliam & Steffen, 2006; Cheng et al., 2013), and is associated with carer QoL, despite limited literature (Crellin et al., 2014; Farina et al., 2017). Positive appraisals of caregiving can

serve as a mediator between caregiving stress and wellbeing (Tarlow et al., 2004), improving caregiving competence, and self-rated health (Belle et al., 2006; Cheng et al., 2013). These findings emphasise the importance of mediating factors, such as social support and positive coping skills, for sustaining QoL in dementia carers, contributing similarly for DWC and DNWC.

Independent of working status, for both the EQ-5D and WHO-5, being male was associated with better QoL and wellbeing. This finding is in common with previous research (Sharma et al., 2016) reporting greater role-strain in female dementia carers, and better adaptation to the caregiving role by male carers (Braun et al., 2009). Younger age was also significantly associated with better EQ-5D scores, consistent with research showing higher levels of depression and physical illness and a diminished QoL in older adult dementia family carers (Schulz & Sherwood, 2008; Schölzel-Dorenbos et al., 2009; Fonareva & Oken, 2014). This also may reflect that time spent caring (Bruvik et al., 2012) and length of time caring (McLennon et al., 2011) is negatively correlated with reduced QoL (as measured by the Short-Form Health Survey and QoL-AD (Alzheimer's Disease scale) (Farina et al., 2017). Age did not significantly predict WHO-5 wellbeing scores.

A strength of this study is the relatively large sample size of DWC compared to previous research. In addition to the advantages of more in-depth analyses of the impact of working status, this large dataset also provided a broader set of measures, producing more insight into the potential for differential effects of the role of psychological factors, carer experience and social influences among DWC versus DNWC.

This study also has limitations. First, even though our sample was stratified by age, we still had a much larger sample of DNWC than DWC. However, this is unsurprising since many family carers give up work to provide full-time care (HMG, 2014). Second, measures included in this study were a selected subset from those available in the IDEAL dataset, and other factors that could impact carer QoL and wellbeing may not have been captured. However, while the absence of a robustly developed measure of disease-specific carer QoL has been identified by previous reviews (Farina et al., 2017; Page et al., 2017b), it is hoped that newly developed measures of carer QoL (SIDECAR and C-DEMQOL) help address this gap (Daley et al., 2018; Oyebode et al., 2018). Methodologically, the cross-sectional nature of the study, without latent factor and mediation analyses, precludes conclusions about causations between variables. Also, using stepwise regression for the exploratory component of the analysis (step 3) can lead to elevated type I error (i.e. false positives) and therefore future research should seek

to confirm these findings. Finally, as the caregivers in this study supported persons with different dementia diagnoses, even though we excluded dementia carers of people with FTD, it is possible that further variations in QoL and wellbeing outcomes amongst DWC and DNWC may have emerged based on diagnostic differences.

In conclusion, this chapter demonstrated that DWC reported better QoL, as measured by the EQ-5D. An exploration of work-life conflicts, and a more thorough analysis of the relationship between different measures of QoL and work-life conflict, would contribute to our understanding of the specific factors that impact the broad concept of QoL for dementia carers who are balancing work and care. Through improved understanding, we can ensure provision of support to minimise differences in QoL between DWC and DNWC.

Chapter 6:

Exploring the bidirectional impact of work-life conflict among dementia working carers

6.1 Introduction

In this chapter I explore the quantitative findings from the primary sample of DWC. The quantitative instruments included in the structured interview explored in more depth how work impacts on family life, and how family life impacts on the work role. As discussed in Chapter 1, working family carers are faced with the dilemma of balancing conflicting demands associated with caregiving and employment duties, which can affect their wellbeing outcomes (Hoff et al., 2014), where work may interfere with family time and vice versa (Greenhaus & Beutell, 1985). Employment demands alone are multifaceted, and composed of the work environment, job duties, and exposure to risks (Schaufeli & Bakker, 2004), in addition to the physical, psychological, social and commanding aspects of the job that require sustained psychological (cognitive or emotional) concentration. There have been many detrimental effects of work-family conflict identified by research which include: job dissatisfaction, job turnover, depression, life and marital dissatisfaction (Allen et al., 2000). Family-work conflict has been described as inter-role conflict where the general demands of family, time devoted to family, and strain created by the family, interfere with performing work-related tasks (Netemeyer et al., 1996). The effects of caring on work performance were also noted and include: lateness; absenteeism; increased sick leave; loss of energy; a greater likelihood of making mistakes at work (Phillips, 1995; cited in Hoff et al., 2014). The extent to which family interferes with work is dependent on care demands, determined by the care recipient's needs and measured by the amount of care required and the time invested in caring responsibilities (Jones & Fletcher, 1996). However, employment has also been associated with positive wellbeing outcomes (Hillage & Pollard, 1998), including: respite from caregiving responsibilities; protection against caregiving stress; increased financial resources (Healthways & Coughlin, 2010; Utz et al., 2011); satisfaction from work-based achievements; greater social integration. In addition to securing financial benefits, work is also perceived as enhancing the carers' own lives and the lives of those of those they provide care to (Utz et al., 2011; DWP, 2014). These findings imply that when the balance

between work and family life is sustained, carers are protected from caregiving strain, resulting in less stress.

In my literature review, I described how DWC are negatively affected by greater care-recipient dependence needs, which is exacerbated by the requirement to combine employment with caregiving (Hughes et al., 2013; cited in Cheng, 2017; Nurfatihah et al., 2013; Wang et al., 2013; Kimura et al., 2015; Alpass et al., 2017). Wang et al. suggested that greater caregiving demands were associated with poorer psychological wellbeing for carers who had high work-life conflict and were less prepared for high caregiving demands. For working family carers with low work-care conflict, however, higher preparedness was associated with decreased role strain, while combining work and care also had positive associations with resilience and adaptive coping. These findings imply that DWC coping strategies are particularly significant for sustaining wellbeing.

Based on previous findings, this chapter seeks to develop a deeper understanding of the relative contribution of factors of caregiving experience, care-recipient dependence, coping strategies, work-to-family/family-to-work conflict to one measure of carer wellbeing. Specifically, the analyses will explore whether these factors are predictive of high or low wellbeing among DWC in the primary cohort. Secondly, it explores whether wellbeing is associated with impaired everyday functioning, and whether this contributed to the work-to-family/family-to-work impact on wellbeing.

Exploring both overlapping measures, and measures specific to the newly recruited primary sample, the following questions were asked:

1. Are wellbeing differences associated with differences in the caregiving experience, family-to-work and work-to-family conflict, coping strategies, care recipient dependence in the primary sample of DWC?
2. Is poorer wellbeing associated with impaired everyday functioning and does this contribute to the work-to-family/family-to-work impact on wellbeing in the primary sample of DWC?

6.2 Methods

This chapter focuses on the quantitative data from the semi structured interview with the independent primary sample of DWC. It explores

1. The demographic factors among the DWC in the larger cohort (full sample) and the primary cohort. As there were limited differences in group size between the full sample (n=215) and sub sample (n=190), overall descriptives were only compared between the full sample and primary sample.

2. The comparative scores from the six overlapping measures (WHO-5 wellbeing; role captivity; caregiving competence; management of situation; positive aspects of caregiving; care-recipient dependence) between the full sample and primary sample. As with the grouping of the variables in the larger cohort, these measures were grouped according to: wellbeing; caregiving experience; care-recipient dependence (explored as an independent variable).

3. The data from the additional instruments selected to further explore the work-life conflict, work-life balance, and indices of wellbeing among the primary sample of DWC. In line with the qualitative method selected for this study (semi-structured, solution-focused interviews), the quantitative exploration of work-life balance was selected to represent the structure of the semi-structured interviews, which assessed the bidirectional impact of work-to-care, and care-to-work responsibilities on: physical health; mental health; everyday functioning; the coping strategies employed to manage daily challenges.

Based on the additional measures selected for the primary sample, the caregiving experience was represented by: role captivity; positive aspects of caregiving; caregiving competence; management of situation; caregiving burden (personal strain and role strain). Care-recipient dependence was represented by the Dependence Scale. Coping strategies were represented by the Brief COPE Index sub-scales (problem-focused coping, emotion-focused coping, dysfunctional coping). Everyday functioning was represented by: The Cognitive Failures Questionnaire (CFQ total); the Attentional Control Scale (ACS total). The Work-Life Conflict Scale (Carlson et al., 2000) was selected to represent the bidirectional challenges in balancing work and family life. The work-life experience was represented by: time-based work-to-family conflict; strain-based work-to-family conflict; behaviour-based work-to-family conflict. The life-work experience was represented by: time-based family-to-work conflict; strain-based family-to-work conflict; behaviour-

based family-to-work conflict. While the findings from the larger cohort also identified some differences in DWC and DNWC QoL that were associated with gender and age, these will not be explored in the primary sample due to a small size of the sample. Therefore, covariates associated with age, gender, carer-dyad relationship, and care-recipient status were not interrogated in this study.

6.3 Design and Analyses

Between group comparisons between the full and primary sample on demographic sand overlapping measures were made using independent samples t-tests. Parametric tests are appropriate for ordinal data where there is a normal distribution of scores. In this study, the significance level for the parametric tests were set at the conventional 5% and the confidence level was 95%. (Field, 2013). In the primary sample, wellbeing scores were split between DWC with poor wellbeing and good wellbeing. Poor wellbeing scores were decided on the basis that scores fell below a score of 13, based on indications that a raw score below 13 on the WHO-5 indicates poor wellbeing (Bech, 2004). Scores on measures associated with the primary sample were then compared using independent samples t-tests. To further explore impact of everyday functioning on wellbeing, bivariate correlations were performed to explore the contribution of work-to-family/family-to-work impact on total ACS score and total CFQ scores.

6.4 Demographic factors: How representative is the primary sample of the larger IDEAL sample?

The characteristics of the primary dementia working carer sample

Most DWC interviewed were in paid employment (23 out of 24), with only one DWC in voluntary employment. More than half (15 out of 24) of DWC were living with the PwD, and the remainder lived in close proximity (i.e. either in their own homes or in care homes). The majority of DWC were in eminent occupations (i.e. Managers, Business owners etc.) or held employment contracts which were flexible or offered more flexibility (i.e. self-employed/freelance). Full DWC demographics are described in Table 6.1.

Table 6.1: Dementia working carers – Demographics

DWC	Age	Gender	Race	Occupation	Employment arrangement	Weekly working hours	Living arrangement	Carer-dyad relationship
1	47	F	White, British	Teaching fellow/PhD	Fixed-term	32 hours	Together	Daughter
2	40	M	White, British	Business Analyst	Part-time/Flexible/Permanent	21 hours	Together	Son-in-law
3	62	F	White, British	Cleaner	Flexible	6 hours	Together	Spouse
4	54	F	White, British	Research Fellow	Fixed-term	11.5 hours	Apart	Daughter
5	57	F	White, British	Administration Manager	Permanent/Part-time	24 hours	Apart	Daughter
6	47	F	White, British	Mental health trainer/consultant	Self-employed/Part-time/Flexible/Freelance/Zero hours	5-10 hours	Apart	Daughter
7	51	M	White, British	Manager	Full-time/Permanent	35+ hours	Together	Spouse
8	41	F	Black, African	Care worker	Full time	24-30	Together	Spouse
9	79	M	White, British	Farmer (main role)	Self-employed	Up to 10	Together	Spouse
10	41	F	White, British	Community cookery worker	Self-employed	28-37 hours	Together	Grand-daughter
11	66	M	White, British	Dementia support group co-ordinator	Voluntary	6-8 hours	Together	Spouse
12	58	M	White, British	Bus driver	Full-time	39 hours	Apart	Son
13	79	F	White, British	Lifeguard trainer	Part-time	4 hours	Together	Spouse
14	45	M	White, British	Manager/Adult education tutor	Part-time/Freelance	30 hours	Apart	Son
15	63	F	White, British	School Secretary	Full-time	37 hours	Apart	Daughter
16	54	F	White, British	Occupational therapist	Full time,	37.5 hours	Apart	Daughter
17	55	F`	White, British	Teacher	Flexible, part-time	20 hours	Together	Daughter
18	40	F	White, British	Journalist and copy writer	Self-employed	30-40	Apart	Daughter
19	61	F	White, British	General Duty Manager - Bookshop (main role)	Part-time/Flexible/Permanent/Zero hours	Up to 21 hours	Apart	Daughter
20	54	M	White, British	Business owner	Freelance	30+ hours	Together	Son
21	62	F	White, British	Foster carer	Self-employed	Continuous	Together	Daughter
22	73	F	White, British	Business owner	Self-employed	15+	Together	Spouse
23	64	M	White, British	Director	Self-employed	4	Together	Spouse
24	40	F	White, British	Clinical Support Worker	Full-time	37.5 hours	Apart	Daughter

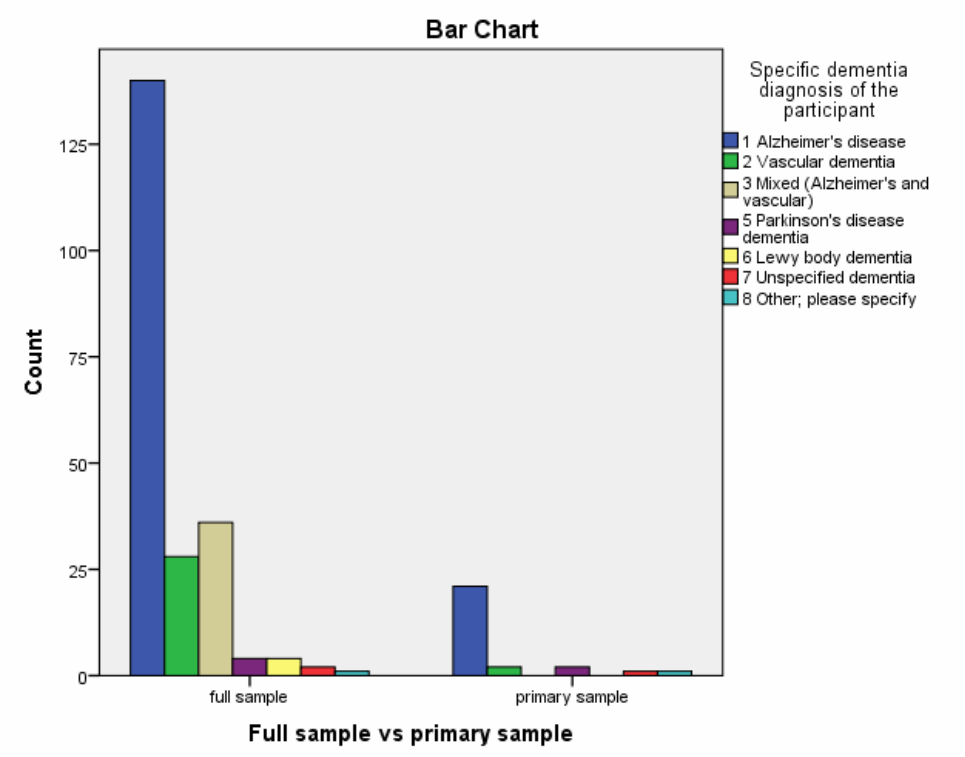
Age

Among the primary sample of DWC, the mean age (56.37 years) was slightly older than the larger cohort (55.5 years).

Dementia diagnosis

As shown in bar chart 6.1, most DWC in the larger cohort (n=140, 65%) and primary cohort (n= 21, 87.5%) were caring for persons who had been diagnosed with Alzheimer's disease.

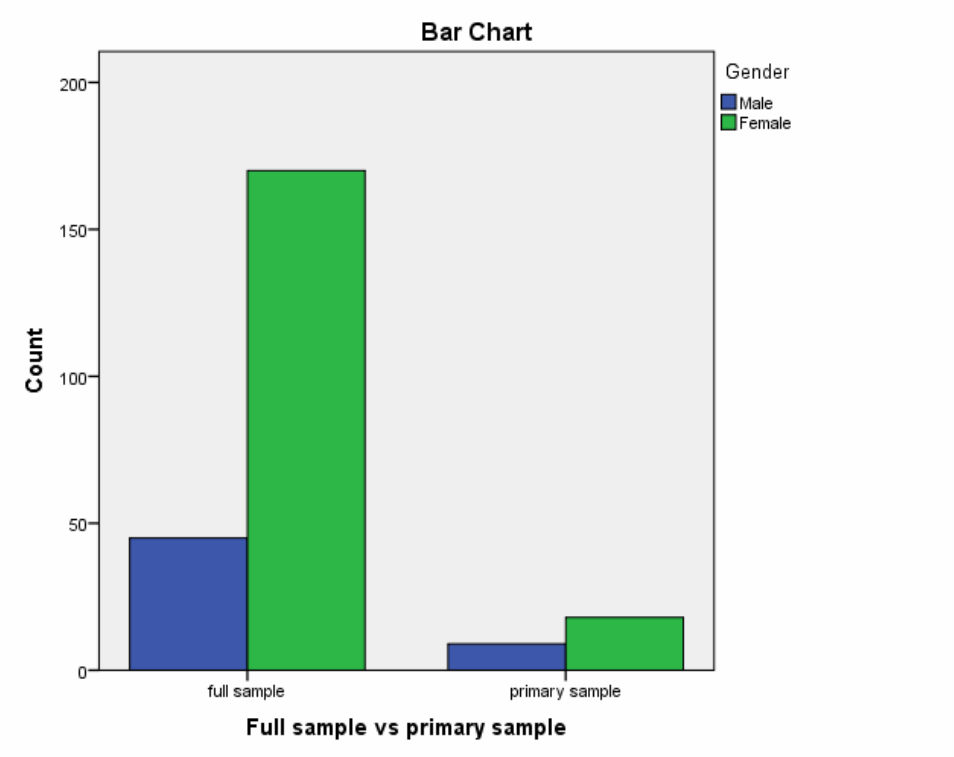
Bar chart 6.1: Dementia diagnosis (full sample versus primary sample)



Gender distribution

As with the gender differences found in the larger cohort, most of the DWC in the larger cohort (n=175, 79%) and primary sample (n=18, 75%), were females (bar chart 6.2).

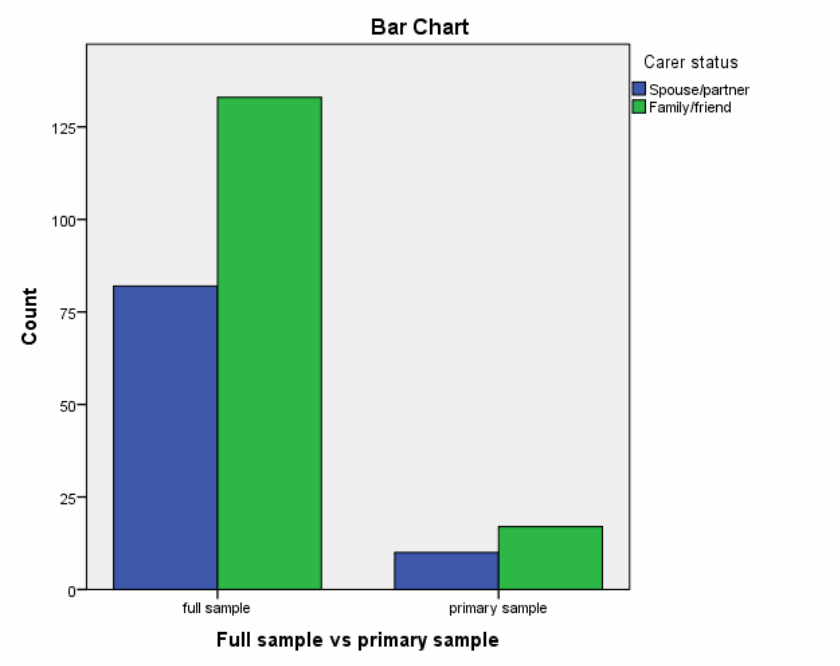
Bar chart 6.2: Gender distribution of dementia working carers (full sample versus primary sample)



Carer-dyad relationship

As seen in bar chart 6.3, the majority of DWC in the larger cohort and primary sample were family/friends i.e. adult children/in-law, grand-children, nieces/nephews, comprising 70.8% (n=17) in the primary sample, and 61.8% (n=127) in the larger cohort.

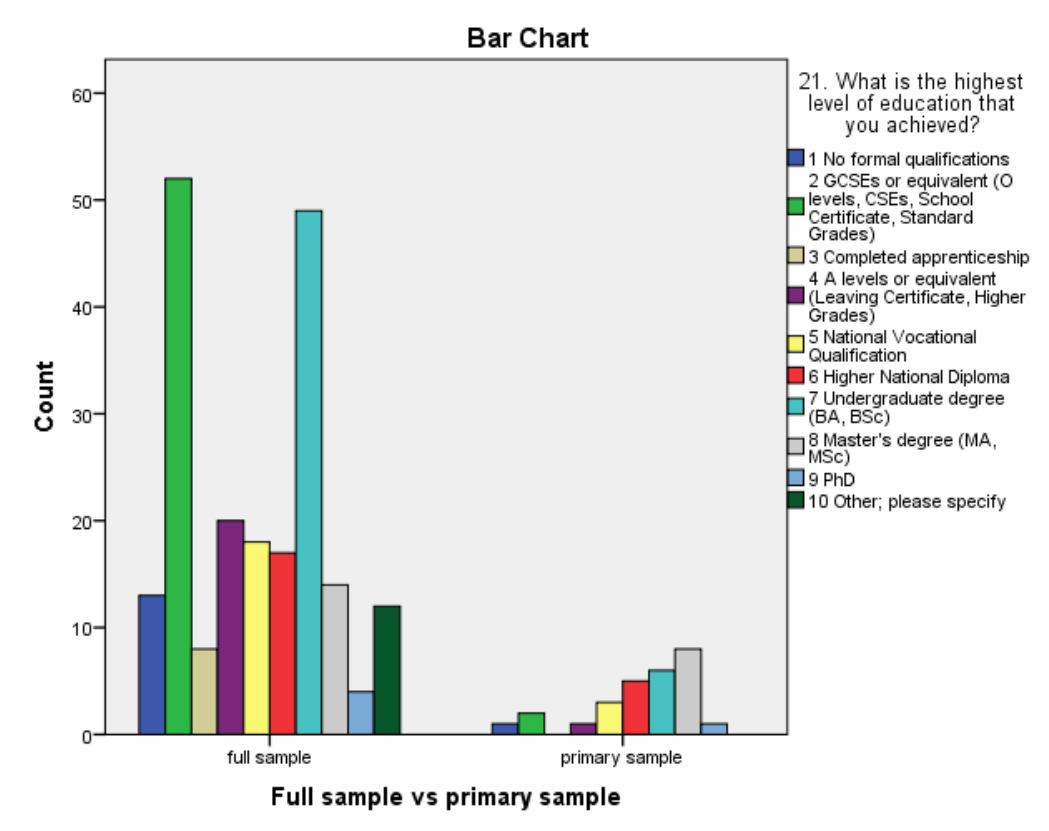
Bar chart 6.3: Carer-dyad relationship (full sample versus primary sample)



Education level of dementia working carers

As shown in bar chart 6.4, the majority of DWC in the larger cohort (n=138, 61.7%) had a standard level of education (below undergraduate degree), while just over half (n=15, 55.5%) of DWC in the primary sample had a higher education level (undergraduate degree or above).

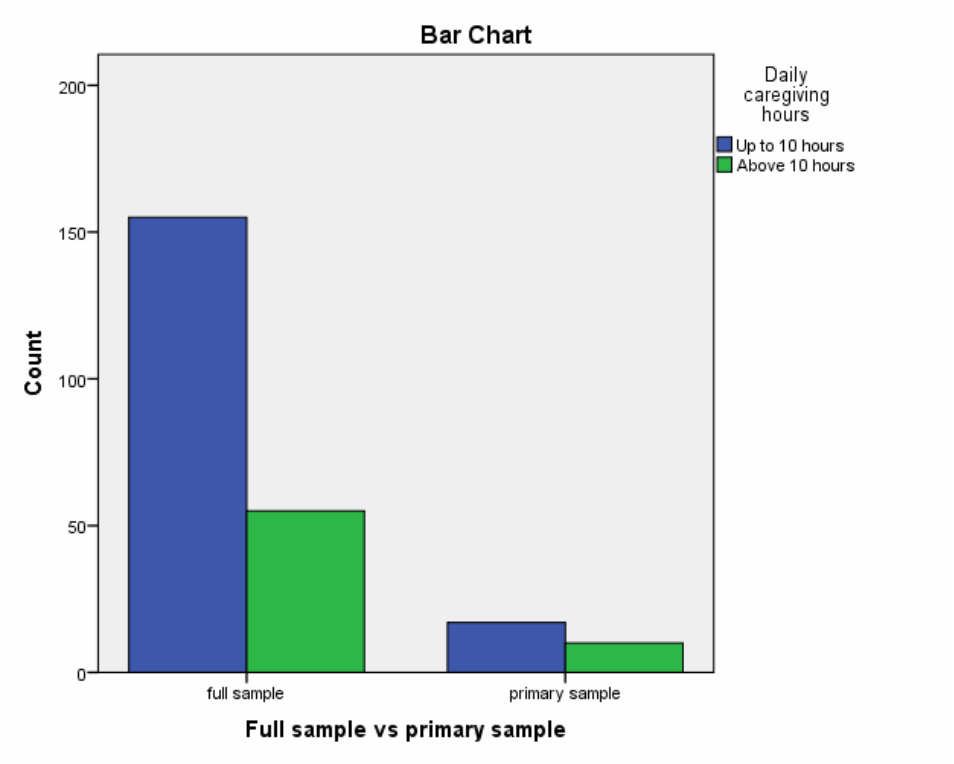
Bar chart 6.4: Level of education (full sample versus primary sample)



Daily caregiving hours

On average, 73.8% (n=155) of DWC in the larger cohort provided up to ten hours of daily care, while 62.9% (n=17) of DWC in the primary sample provided up to ten hours of daily care (see bar chart 6.5) – note: exact daily hours of care were not interrogated in the full sample (IDEAL study), because the hourly data was not collected.

Bar chart 6.5: Daily caregiving hours (full sample versus primary sample)



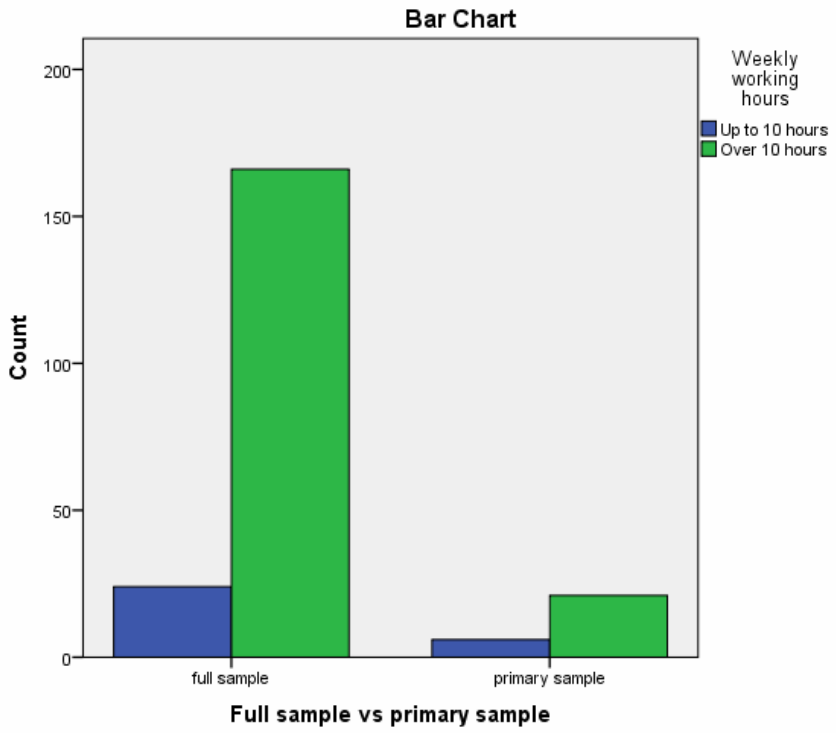
Occupational profile

DWC in the full and primary cohort, were categorised according to whether they were in: manual i.e. labour; administrative i.e. secretarial/PA/Clerk; or strategic Managerial/supervisory/Therapeutic/Teaching positions. However, 121 (56.2%) of individuals in the larger cohort did not provide their occupation and therefore occupational status could only be ascertained for approximately half of the sample (n= 94). The majority of DWC in both the larger (n=66, 56.3%) and primary cohort (n=14, 51.8%) held strategic positions.

Weekly working hours

The data are split by ≤ or > 10 hours per week for DWC in bar chart 6.6 (note: 25 (11.6%)) of individuals in the IDEAL sample did not provide weekly working hours and therefore were not included in this descriptive)). The majority of DWC in the larger cohort (n=167, 87.3%) worked over 10 hours a week. As with the larger cohort, the majority of DWC in the primary sample (n=21, 77.7%) worked more than 10 hours a week, with an average of 24.3 hours worked in a week.

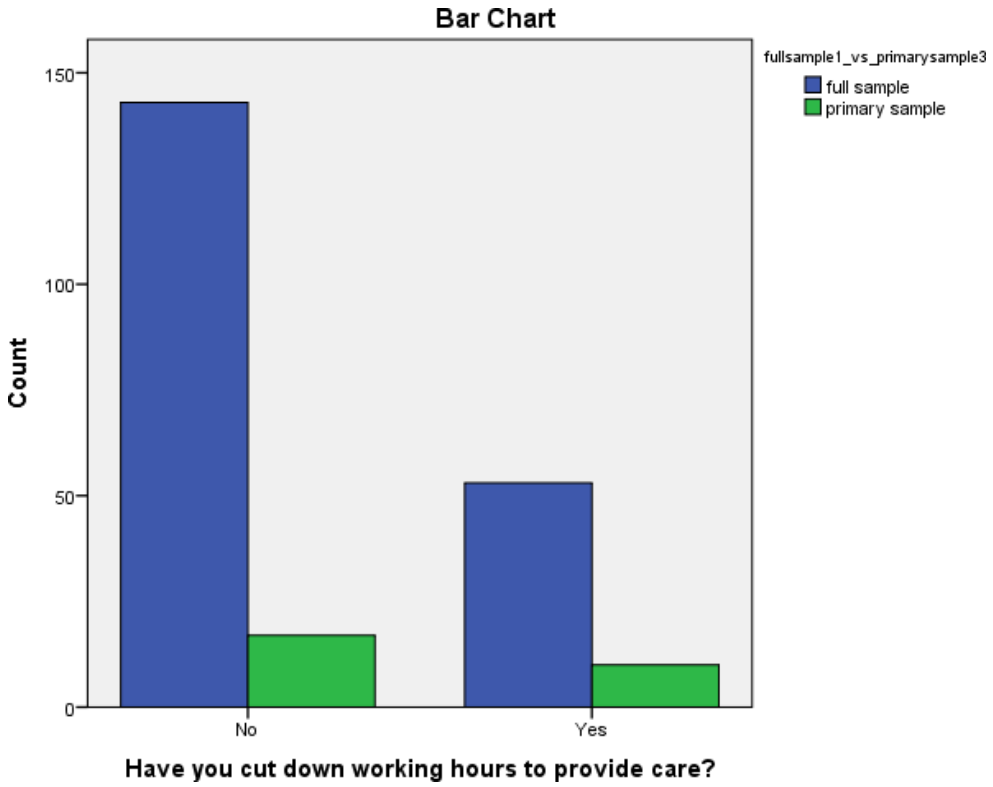
Bar chart 6.6: Weekly working hours (full sample versus primary sample)



Has work been reduced to provide care?

The bar chart (6.7) shows that in the full sample, the majority (n=145, 74.6%) had not reduced their hours. Similarly, in the primary sample, the majority (n=17, 62.9%) of DWC had not reduced their working hours.

Bar chart 6.7: Have you cut down working hours to provide care? (full sample versus primary sample)



Ethnicity

As with the larger sample of DWC, most carers in the primary cohort were White (English/Welsh/Scottish/Northern Irish/British - n=26), with only one carer of Black/African descent.

6.4.1 Interim Summary: Demographics

The descriptive data demonstrate that the DWC in the larger IDEAL cohort and in the primary cohort were similar on most measures. Both groups were providing care recipients with Alzheimer's disease, and most were female, British, Caucasian, in their mid-fifties, family/friend carers, provided up to 5 hours of daily care, worked more than 10 hours weekly, held strategic occupations, and had not reduced work to provide care. Differences between groups occurred in educational attainment, with more DWC in the primary cohort with undergraduate/postgraduate experience.

6.5 Wellbeing, care recipient dependence, and caregiving experience in dementia working carers: How representative is the primary sample of the larger IDEAL sample?

The next stage of the analysis of the primary DWC data was to explore the primary sample in terms of overlapping measures in the IDEAL study, to assess how comparable the carers in the primary sample were to the full sample of DWC in the IDEAL cohort.

Table 6.2: Means, standard deviations, and statistical outcomes for overlapping measures between full sample and primary sample

Overlapping measures	Primary sample and full sample comparisons	N	Mean	SD	P
WHO-5 (Wellbeing)	Full sample	208	14.15	4.60	.01
	Primary sample	27	11.77	5.45	
Dependence	Full sample	198	5.65	2.49	p≤.001
	Primary sample	27	8.85	2.79	
Management of situation	Full sample	207	9.84	1.94	p<.01
	Primary sample	27	10.88	2.08	
Role captivity	Full sample	206	5.45	2.07	p<.01
	Primary sample	27	6.88	2.72	
Positive aspects of caregiving	Full sample	206	28.60	7.03	.17
	Primary sample	27	26.59	8.33	
Caregiving competence	Full sample	208	8.95	1.60	p<.01
	Primary sample	27	8.00	2.11	

Table 6.2 shows the means for the full-sample (n=215) and primary sample (n=27). Independent samples t-tests indicated that the group means for positive aspects of caregiving: $t(206) = 1.36$, $p = >.05$ were not significantly different. All other measures were significantly different between groups (all ps<.05). The primary sample were caring for PwD with greater dependence needs (M=8.85, SD= 2.79) than the full-sample (M=5.65, SD=2.49). Management of situation was rated as higher among the primary sample (M=10.88, SD=2.08) than the full sample (M=9.84, SD=1.94). Role captivity was rated as greater among the primary sample (M=6.88, SD=2.72) than the full sample

(M=5.45, SD=2.07). Caregiving competence was rated as lower in the primary sample (M=8.00, SD=2.11) than among the full sample (M=8.95, SD=1.60). Overall wellbeing was lower among the primary sample (M=11.77, SD=5.45) than the full-sample (M=14.15, SD=4.60).

6.5.1 Interim Summary: Wellbeing, care recipient dependence, and caregiving experience

These findings suggest that the primary sample of DWC were experiencing more strain, poorer overall wellbeing, and rated themselves as having lower caregiving competence scores, which may be indicative of caring for care recipients with higher dependency needs. However, DWC in the primary sample were more confident that they had not lost aspects of their personality through caring – as indicated by greater management of situation scores. The implications of these findings are that the DWC in the primary sample are potentially less representative of the DWC in the full IDEAL sample, and that they may not represent DWC of care-recipients with low dependency needs. Therefore, subsequent interpretation of the primary sample findings should be made with this caveat in mind.

6.6 Exploring the caregiving experience, family-to-work and work-to-family conflict, coping strategies, and everyday functioning on the wellbeing of dementia working carers in the primary sample

For the next stage of analysis, the primary sample was divided according to their scores for the WHO-5 Well-Being Index, and comparative analyses sought to establish whether individuals reporting good versus poor wellbeing also reported a. differences in care recipient dependence, caregiving experience, coping strategies, family-to-work and work-to-family conflict; b. differences in everyday functioning. Finally, I compared differences in everyday functioning and whether this contributes to the work-to-family/family-to-work impact on wellbeing in the primary sample of DWC.

Care-recipient dependence (represented by the Dependence Scale)

Independent samples t-tests indicated that the group means for care-recipient dependence were not significantly different for the two levels of wellbeing: t(25) = -.362, p = > .05-.

The caregiving experience

Table 6.3: Caregiving experience measures reported among dementia working carers with poor versus high wellbeing in the primary sample

Caregiving experience	Poor wellbeing versus high wellbeing	Mean	SD	P
Management of situation	Poor wellbeing	6.62	2.02	.43
	High wellbeing	7.27	2.19	
Positive aspects of caregiving	Poor wellbeing	25.25	8.52	.32
	High wellbeing	28.54	8.02	
Role captivity	Poor wellbeing	24.68	13.09	.01
	High wellbeing	11.81	10.78	
Caregiving competence	Poor wellbeing	20.93	9.34	p<.001
	High wellbeing	30.90	9.70	
Caregiving burden (personal strain)	Poor wellbeing	14.00	3.88	p<.01
	High wellbeing	7.72	4.62	
Caregiving burden (role strain)	Poor wellbeing	15.06	3.54	p<.01
	High wellbeing	8.81	4.30	

Table 6.3 shows the means caregiving experience ratings for DWC with high versus poor wellbeing. Independent samples t-tests indicated that the group means for management of situation: t(25) = -.789, p = > .05, and positive aspects of caregiving: t(25) = -1.01, p = >.05 were not significantly different. All other measures were significantly different between groups (all ps<.05). DWC who had higher scores in caregiving competence (M=30.90, SD=9.70), lower scores in role captivity (M=11.81, SD=10.78) and lower scores in caregiving burden personal strain (M=7.72, SD=4.62) and rolestrain (M=8.81, SD=4.30) reported significantly higher wellbeing than those with lower caregiving competence (M=20.93, SD= 9.34), higher role captivity (M=24.68, SD=13.09), and greater caregiving burden personal strain (M=14.00, SD=43.88) and role strain (M=15.05, SD=3.54).

Coping strategies

Table 6.4: Coping strategies scores among dementia working carers with poor versus high wellbeing in the primary sample

Coping strategies	Poor wellbeing versus high wellbeing	Mean	SD	P
Emotion-focused	Poor wellbeing	23.50	4.16	.69
	High wellbeing	22.81	4.81	
Problem-focused	Poor wellbeing	16.75	3.10	.26
	High wellbeing	15.09	4.45	
Dysfunctional	Poor wellbeing	33.18	5.16	.18
	High wellbeing	35.54	3.04	

Table 6.4 shows the means for DWC with high versus poor wellbeing scores. Independent samples t-tests indicated that the group means for emotion-focused coping strategies: t(25) = .393, p = > .05, problem-focused coping strategies: t(25) = -1.14, p = >.05, and dysfunctional coping strategies: t(25) = -1.35, p = >.05 were not significantly different between groups.

Family-to-work and work-to-family conflict

Table 6.5: Measures of family-to-work/work-to-family conflict among dementia working carers with poor versus high wellbeing in the primary sample

Family-to-work/Work-to-family conflict	Poor wellbeing versus high wellbeing	Mean	SD	P
Family-to-work conflict (time based)	Poor wellbeing	9.43	2.80	.03
	High wellbeing	6.36	4.43	
Work-to-family conflict (time based)	Poor wellbeing	7.62	2.33	.08
	High wellbeing	5.81	2.92	
Family-to-work conflict (strain based)	Poor wellbeing	10.31	2.98	p<.001
	High wellbeing	5.09	2.70	
Work-to-family conflict (strain based)	Poor wellbeing	7.75	2.67	.10
	High wellbeing	5.72	3.55	
Family-to-work conflict (behaviour based)	Poor wellbeing	8.18	3.29	.89
	High wellbeing	8.00	4.07	
Work-to-family conflict (behaviour based)	Poor wellbeing	8.37	2.72	.10
	High wellbeing	6.54	2.91`	

Table 6.5 shows the means for DWC with high versus poor wellbeing scores. Independent samples t-tests indicated that the group means for family-to-work conflict (time based): t(25) = 2.21, p = < .05 (two-tailed), and family-to-work conflict (strain based): t(25) = 4.64, p = <.01 (two-tailed) were significantly different between groups. All other measures were not significantly different between groups (all ps>.05), though work-to-family conflict (time-based) showed a trend towards significance: t(25) = 1.78, p = .08. DWC with lower scores in time based family-to-work conflict (M=5.09, SD=2.70), and lower scores in strain based family-to-work conflict (M=11.81, SD=10.78) had significantly higher wellbeing than those with higher time based family-to-work conflict (M=9.43, SD= 2.80), and higher strain based family-to-work conflict (M=10.31, SD=2.98).

Everyday functioning

Table 6.6: Measures of everyday functioning among dementia working carers with poor versus high wellbeing scores in the primary sample

Everyday functioning	Poor wellbeing versus high wellbeing	Mean	SD	P
CFQ (total score)	Poor wellbeing	55.06	17.27	.16
	High wellbeing	64.00	13.77	
ACS (total score)	Poor wellbeing	51.37	5.14	.61
	High wellbeing	50.45	3.64	

Table 6.6 shows the means for DWC with high versus poor wellbeing scores. Independent samples t-tests indicated that the group means for CFQ (total score): t(25) = -1.42, p = >.05, and ACS (total score): t(25) = .510, p = >.05 were not significantly different between the groups. However, exploratory analyses (Table 6.7) indicated that strain-based work and life conflict (i.e. family-to-work conflict) was positively correlated with CFQ total scores, implying that strain from family to workplace was associated with higher numbers of everyday cognitive failures.

Table 6.7: Bivariate correlations between measures of everyday functioning and strain-based work-to-family conflict and strain-based family-to-work conflict among the primary cohort

		Strain-based work-to-family conflict	Strain-based family-to-work conflict	ACS total	CFQ total
Strain-based work-to-family conflict	Pearson Correlation	1	.549**	-.105	.331
	Sig. (2-tailed)		.003	.604	.092
	N	27	27	27	27
Strain-based family-to-work conflict	Pearson Correlation	.549**	1	-.093	.643**
	Sig. (2-tailed)	.003		.646	.000
	N	27	27	27	27
ACS total	Pearson Correlation	-.105	-.093	1	-.012
	Sig. (2-tailed)	.604	.646		.953
	N	27	27	27	27
CFQ total	Pearson Correlation	.331	.643**	-.012	1
	Sig. (2-tailed)	.092	.000	.953	
	N	27	27	27	27
**. Correlation is significant at the 0.01 level (2-tailed).					

6.6.1 Interim Summary: caregiving experience, family-to-work conflict and work-to-family conflict, coping strategies, and everyday functioning on the wellbeing of dementia working carers in the primary sample

The analyses between members of the primary sample who rated their wellbeing higher or lower than the normative value for this test showed that lower role captivity, reduced caregiving burden (personal and role strain), and higher caregiving competence were associated with higher wellbeing scores for DWC. Time based and strain-based family-to-work conflict measures were significantly lower among DWC with higher wellbeing. There was no difference in reported measures of everyday functioning between individuals reporting poor versus higher wellbeing scores. However, exploratory analyses revealed that strain-based family-to-work conflict was significantly correlated with cognitive failures. Therefore, while it is unlikely that differences in performance competencies at work contribute to the family-to-work and work-to-family conflict impacts differences in wellbeing between the groups, there is a significant impact of strain

experienced from family in the workplace, and a greater likelihood of impaired everyday functioning.

6.7 Discussion

This chapter aimed to use quantitative data from the structured interviews with the primary sample of DWC to provide a more in-depth exploration of how work impacts on family life, and how family life impacts on the work role. Comparing the demographic data between DWC in the larger cohort and DWC in the primary cohort, I established that the two groups held similar characteristics. Both were predominantly caring for individuals with Alzheimer's disease. Most DWC in both groups were British (white), female, non-spouses, mid-fifties, and caring for up to 10 hours daily, and working above 10 hours a week. Most DWC also held strategic positions in their employment and had not reduced their working hours to provide care. The main difference highlighted between groups was in educational attainment, whereby the primary sample of DWC overall were more likely to have degree and postgraduate experience. While there was missing data relating to employment contract information for the full sample, higher educational attainment among the primary sample of DWC might indicate that the difference in educational attainment supports more sustainable employment in the primary sample. This is based on research which demonstrates that there is a higher growth in earnings for graduates than for non-graduates over time (Walker & Yu Zhu, 2013). Although unacknowledged, it is likely that a higher education may have longer term benefits for caring needs in later life, if higher salaries can support private respite care and a reduction in working hours.

Comparing wellbeing, care recipient dependence, and caregiving experience between DWC in the full sample and the primary sample revealed that the full and primary sample differed on all measures apart from positive aspects of caregiving. Importantly, the DWC in the primary sample were caring for individuals with greater dependence needs than were the DWC in the full sample. In the primary sample, DWC had poorer wellbeing overall, as well as higher scores in role captivity, and lower perceptions of caregiving competence. However, DWC in the primary sample felt more confident that they had not lost aspects of their personality due to caring. In this case, reduced wellbeing among DWC in the primary sample may be a result of caring for

individuals with greater dependence needs, as has been reported by previous research (Nurfatihah et al., 2013; Wang et al., 2013).

The final section of this chapter explored the questions highlighted in the introduction, to further interrogate differences between DWC who reported poor versus high wellbeing scores. The data demonstrated that DWC with better wellbeing scores had lower caregiving burden (personal strain and role strain) and role captivity, and a greater sense of caregiving competence. Similar studies have found that greater carer wellbeing is associated with reduced negative emotions such as stress, burden, depression (Cunningham et al., 2018), while higher caregiver burden has been linked to poorer psychological wellbeing (Alvira et al., 2015). The differences between the groups reported here are consistent with positivity in the carer role supporting better wellbeing scores, but it is not possible to deduce from this data whether these differences reflect traits and pre-existing personality styles, or whether they reflect better adaptation to the carer role. For instance, no differences were found between DWC with poor versus high wellbeing scores, which may be reflective of the fact that DWC in the primary sample felt that they were less likely than the full IDEAL cohort to report a loss in aspects of their personality. This may be indicative of a pre-existing personality style among the primary sample, which served to protect DWC with better wellbeing. This is an area for future study.

When work-to-family and family-to-work conflict was compared between groups of DWC who reported high versus low wellbeing, lower time based and strain-based family- to-work conflict were associated with higher wellbeing outcomes. These findings imply that for DWC the interference of caregiving responsibilities with the working role are stronger than the interference of work with family responsibilities. This could be taken to imply that the work environment is accommodating the caring responsibilities well, but that the carers experienced difficulty in separating themselves from care responsibilities when they were at work, and experienced interference based on the time allocated to family responsibilities. Previous research has found that greater caregiving demands are associated with poorer psychological wellbeing for DWC with high work-life conflict, and more positive coping and decreased role strain among DWC with low work-care conflict (Wang et al., 2013). However, this previous research failed to interrogate the bidirectional impact of family-to-work and work-to-family conflict domains. By exploring the time, strain, and behaviour-based bidirectional impact work-to-family and family-to-work conflict among DWC, the present study provides a much

more detailed picture. The data indicate that the strain and time limitations associated with the caregiving role on work duties were most threatening to the sustainability of family-to-work work-life reconciliation for DWC, while behaviour-based ones (i.e. incompatible behavioural expectations across roles) were not significant factors. Furthermore, higher family-to-work interference has been associated with more mistakes at work (Phillips, 1995). In this chapter, reported wellbeing differences between DWC groups did not differentially impact everyday functioning. However, the positive correlation between strain-based family-to-work conflict and number of everyday cognitive failures indicated that while overall reported wellbeing was not impacted by impaired everyday functioning, there was a significant effect of caregiving strain in the workplace, and greater cognitive errors.

In conclusion, the synthesis of data relevant to DWC in the full sample and primary sample, demonstrated both overlap and differences in terms of the subjective experience of the two groups. The deeper analysis of the primary sample experiences provided novel data regarding the potential impact of the caregiving experience, care-recipient dependency needs, and the mutuality of work and life interference on wellbeing. The primary sample differed from the larger sample in the sense that they were caring for individuals with greater dependency needs and had a better sense of how they managed the caregiving role. The in-depth analyses found elements common to higher wellbeing scores (i.e. reduced caregiving burden and family-to-work conflict) among DWC. The findings do not allow directionality to be assigned to these associations, however.

The in-depth questionnaire used to assess work-to-family and family-to-work conflict provided a greater understanding of the bidirectional work-to-family/family-to-work influences, which has been absent from previous research among DWC. Other indicators of higher wellbeing found in research among DNWC and DWC however (i.e. lower care-recipient dependence, positive coping strategies, greater everyday functioning), were not associated with higher wellbeing scores. In the next chapter, I will explore further the challenges to sustainable reconciliation for DWC in the primary sample, using semi-structured interviews and novel qualitative approaches.

Chapter 7:

The experience of the everyday life of dementia working carers: The challenges of work-life reconciliation

7.1 Introduction

To gain more understanding of my early quantitative findings on those areas which impact the wellbeing and work-life reconciliation of DWC, it is important to draw on the experience of DWC through their own voice. In this chapter, I first reflect on the literature presented (Chapter 2), the theoretical framework (Chapter 3.3) and my quantitative research findings (Chapters 4-6) which are relevant to the work-care challenges facing DWC. I then present the themes of the qualitative study that takes into account the quantitative data findings addressed in the early part of the thesis. In the final part of this chapter, I summarise the qualitative findings to form an overall conclusion of the challenges facing the primary sample of DWC.

7.2 The challenges of work-life reconciliation of dementia working carers: What we (do not) know so far

As discussed in Chapter 2, more intense caregiving roles can make combining work and care even more difficult for DWC. The challenges to work-life reconciliation for carers relate to the minimal support and services offered (Yeandle & Buckner, 2017). Many researchers (e.g. Arksey et al., 2005; Yeandle et al., 2007; Arksey & Glendinning, 2008; Milne et al., 2013) argue that access to information and advice, affordable good-quality care and support services, a joined-up needs assessment of both the DWC and PwD, and the identification of carers in the workforce by employers, were ongoing concerns for DWC. Moreover, working carers in general and DWC are still not being adequately supported to combine work and care by local authorities in the carer's assessment (Bunn et al., 2016; Carers UK, 2017).

There is clear evidence that DWC have poorer mental health and report greater depressive symptomatology than non-carers (Alpass et al., 2017). When caring for a person with severe stage dementia, it could make combining employment and care roles even more difficult, resulting in lower QoL and poor mental, physical, and social

wellbeing (Nurfatihah et al., 2013; Wang et al., 2013). Kimura et al. (2015) also found that besides the impact on physical and mental health, dementia caregiving is detrimental to the professional role, elevating the need for more professional support. Wang and colleagues' (2011) findings suggest that greater caregiving demands are associated with poorer psychological wellbeing for carers who have high work-life conflict and are less prepared for high caregiving demands. High levels of workplace flexibility and part-time employment could prevent depressive symptoms among working adult and child carers. However, not all DWC have benefitted from those incentives. Further evidence showed the impact of working while caring for a PwD, includes a 'disconnect' between employers' policies and employee experience (EfC, 2011), with DWC expressing dissatisfaction within flexible working arrangements and a lack of awareness of employers' policies.

In the IDEAL cohort, DWC report less confidence than DNWC in their own caregiving competence (Chapter 4.3). In the primary sample, DWC report poorer caregiving experience and wellbeing in comparison to the full IDEAL DWC cohort (Chapter 6.4), which is indicated by higher scores in role captivity, and lower perceptions of caregiving competence. This reduced wellbeing among DWC in the primary sample may be a result of caring for individuals with greater dependence needs, which has been associated with lower QoL and wellbeing (Nurfatihah et al., 2013; Wang et al., 2013; Cheng, 2017). Lower time-based and strain-based family-to-work conflict, higher caregiving burden (personal strain and role strain), more role captivity, and a lesser sense of caregiving competence were factors associated with poorer wellbeing among the primary sample of DWC. These findings implied that the interference of caregiving responsibilities with the working role are stronger for DWC who experience more pressure from caregiving and time spent on caregiving tasks (King et al., 2014), and suggest that more effort is required by professionals in identifying and responding to carers' support needs.

As highlighted in the challenges theoretical framework in Chapter 3.3, the Theory of Human Need (Doyal & Gough, 1991; Gough, 2004) establishes that our basic needs require the satisfaction of certain intermediate needs based on such areas as a non-hazardous environment, appropriate health care, significant primary relationships, and economic stability. The ability to meet these basic needs is impaired by poor mental health, impaired cognitive skills, and difficulties engaging in social activities (Gough, 2004). When demands are high, the SPM (Pearlin et al., 1990) establishes that multiple factors relating

to the background context of the carer (i.e. care-recipient dependence), can impact subjective stressors (i.e. role overload, caregiving burden) and lead to role strain (i.e. conflict between work, caregiving and family/social life), and poorer wellbeing (i.e. depression, impaired physical health, and cognitive disturbance). While emotion-focused coping strategies and problem-focused strategies are often associated with positive coping behaviours (Lazarus & Alfert, 1964), emotion-focused coping strategies can lead to dysfunctional coping behaviours i.e. avoidance, and suppressing negative thoughts or emotions (McLeod, 2009), resulting in poor wellbeing outcomes. Role-set theory recognises that various social arrangements can challenge the expectations of individuals included in various roles, leading to intra or inter-role conflict, and is concerned with the circumstances which disrupt social functioning, as well as the social mechanisms which counteract the strains of role-set demands (Merton, 1949, 1957).

What is known about the challenges facing DWC is that caregiving creates an increased risk to mental health which can further impact overall wellbeing when care recipients are in the severe stages of dementia. However, what is not clear is how the day-to-day caregiving experience is perceived by DWC and how this impacts their wellbeing. The quantitative findings (see Chapter 6.5) demonstrate that DWC experience poorer wellbeing based on the time-based and strain-based interference of caregiving on work duties, with a negative caregiving experience being most likely to impact wellbeing. Based on the challenges framework (Chapter 3.3), role-set theory recognises that when multiple roles challenge individual resources, there is an increased likelihood of role conflict. However, it is also important to address the bidirectional impact of work-to-life and life-to-work conflict. Moreover, while some research (i.e. EfC, 2011) has explored the impact of workplace policies for DWC, there is still very little understood about DWC perceptions of the adequacy of existing support, and whether there remain outstanding support needs of DWC at home and in the workplace.

In this chapter, I draw on the objectives of role-set theory to explore how DWC perceive the challenges to sustained work-life reconciliation, and how these challenges impact overall wellbeing. I also reflect on the quantitative findings based on the difficulties experienced by DWC in the full and primary cohort, and whether the challenges reported by the primary cohort of DWC in qualitative analyses explain the early quantitative findings. The analysis is based on the views of twenty-four DWC interviewed and their chosen artifact which represents their work-life balance. The following overarching questions were developed to explore challenges:

- Why does conflict occur between work and care?
- What support could be offered to DWC at a local level (e.g. family, services, employment) and national level (policy) to assist in the balance of work and care responsibilities?

7.3 Methodology

Artifacts were selected by DWC to represent how they perceive the work-life balance. As found in previous research (Frith et al., 2005; Bagnoli, 2009; Rouse, 2013; Douglas et al., 2015), artifacts of personal importance enabled DWC in this study to comfortably reflect on issues that are meaningful to them. Many participants valued the opportunity to reflect on their work-care experiences by choosing a personal object prior to the interview, as illustrated by one of the DWC: '*Good question, I have never thought about what it means by being a dementia working carer. I will have a good think about this and I'm looking forward to choosing an object on this.*' Furthermore, the introduction of a familiar artifact served as an effective method for easing participants into interviews and encouraged discussion of the emotional and personal experiences relating to the challenges of balancing work and care. All the participants interviewed showed enthusiasm when we met because they were eager to discuss the object which was individual to them and their experiences. Drawing on qualitative content analysis described in chapter 3.8.3, I analysed the interview transcripts and open-ended responses in the semi-structured interviews with the artifact, within the conceptual framework associated with the challenges to sustainability. Several challenges to work-life reconciliation for DWC were observed and the emergent themes were associated with: caregiving burden; work, care, and life conflict; and support needs.

7.4 Results

Four out of twenty-four artifacts selected by DWC~~,~~ symbolised the difficulties of achieving work-life balance and were categorised under themes associated with 'caregiving burden' and 'work, care, and life conflict' (see Table 7.1).

Table 7.1 Challenges that the selected artifacts represented, organised by themes

Artifact	Theme 1: Caregiving burden	Theme 2: Work, care, and life conflict
Rubiks cube		✓
Handbag		✓
Carers magazine	✓	
Kitchen weighing scales		✓

7.5 Caregiving burden

The impact of caregiving burden on working life and personal life was a shared concern of the DWC interviewed. For most DWC (19 out of 24), caregiving burden often occurred when the caring role was unexpected and there was little choice because no-one else could fulfil the role, as explained by a DWC:

Researcher: *'Why did you choose to be a working family carer?'*

DWC: *'Let's unpick the notion of choice. Where is the choice? [laughs]. I mean... that was not a CHOICE. We didn't choose any of those things, but mum was diagnosed with dementia. We couldn't really be leaving her on her own anymore. What would we do with her?'* (DWC1)

As discussed in early chapters (e.g. see Chapter 1.2), dementia care is often complex and demanding. Moreover, as dementia, currently, is an untreatable illness with many unknown factors and symptoms, the complexity of dementia caregiving resulted in (9 out of 24 DWC) feelings of 'loneliness', 'isolation' and/or feeling 'trapped' in the caring role, as illustrated:

'…caring can be very isolating and a very lonely experience, and you can sort of feel very trapped in a small world with the person you're caring for…' (DWC14)

'…isolating as well, because nobody really understands [dementia]…' (DWC6)

The above views were further demonstrated by a DWC who presented an available carer's magazine (see Photo 7.1) which was for carers in general but not specific to helping DWC to care for PwD, or for support with sustaining the work, care, and life balance. The carer's magazine therefore, symbolised the sadness and hopelessness that DWC felt when they became dementia carers without knowing what to expect.

Photo 7.1 Care magazine as a lack of clear role definition for dementia working carers (DWC3)

In this instance, the DWC was typical of DWC in the primary and larger cohort based on gender, age, and ethnicity. She was white, British, in her early sixties, the wife of the PwD, and the bread-winner of their household. As with the larger sample, she had also experienced a standard level of education. Unlike DWC in the larger cohort and primary cohort however, this DWC did not have a strategic role, and was in a low-income job. This DWC had very limited informal and formal support and found limited time to self-help by searching for information about dementia, dementia care, and how to be a carer while juggling between work and care. Chapter 4.2 showed that DWC have less

time to commit to the caregiving role in comparison with DNWC. Therefore, it could be argued that it is essential that an accessible, easy-read guide directly related to the work and care role is available to DWC. Such information and guidance would be particularly crucial to those lone DWC who do not have family support or share the caring role.

The lack of understanding of dementia care and the DWC role also impacts on the societal expectations of DWC. Many DWC (16 out of 24) for instance, spoke about the expectations placed on them to *assume* their primary caregiving role, as illustrated by the following DWC:

"It got thrust upon me, I didn't choose it at all [laughs] […] I'm just the only relative, so it falls to me." (DWC24)

7.5.1. Summary: Caregiving burden

The above findings resonated with earlier research evidence (i.e. Robison et al., 2009; Shah et al., 2010; Vitaliano et al., 2011; Zwaanswijk et al., 2013) on caregiving burden for dementia carers, which is associated with *loneliness*, *isolation*, and for some, lack of choice. This was associated with the emotional work (Simpson & Acton, 2013) and emotional labour (Msiska et al., 2014) of dementia carers. For DWC, the implications of the restrictions of primary caregiving, are the very high risks to their autonomy. As shown in Chapter 6.5, the quantitative findings demonstrated that DWC who reported poorer caregiving experience had worse wellbeing than DWC with better caregiving experience. Therefore, the result of caregiving burden is poorer health. The lack of clear description and guidance on the role of DWC and lack of formal and informal care support might also contribute to why DWC have lower caregiving competence and lower confidence in caregiver coping abilities than DNWC (see Chapter 4.3).

7.6 Work, care, and life conflict

According to the DWC interviewed, the work, care, and life conflict were prevalent in the following areas: a) overlapping roles; b) triple-duty caregiving responsibilities; c) their overall wellbeing.

7.6.1 Overlapping roles

Nearly all of the DWC (22 out of 24) interviewed, experienced an overlap between work and life, which created mutual disruption, and impacted overall wellbeing. Several DWC (16 out of 24) referred to the impact of the caregiving role on their working role. Nearly half of DWC (11 out of 24) also described the impact of the working role on their caregiving duties, and private lives. The interrelated challenges between work and care were predominant in some artifacts that DWC selected to demonstrate the complexity of managing all roles. For example, one DWC selected a rubiks cube (Photo 7.2) to symbolise the difficulty of managing one role, whilst juggling multiple responsibilities:

Photo 7.2 Rubiks cube symbolising the difficulty of work-life balance (DWC6)

'...I sort of thought of trying to do a Rubik's cube which I never mastered but I could always manage to do one side, and that's really what it feels like. I can do one of the things I have to do fine, but […] the other side's completely abandoned while you're concentrating on that side, and as soon as you start on another side you mess up the first side.' (DWC6)

Another participant used an upturned handbag (Photo 7.3) to demonstrate how uncontrollable their life had become:

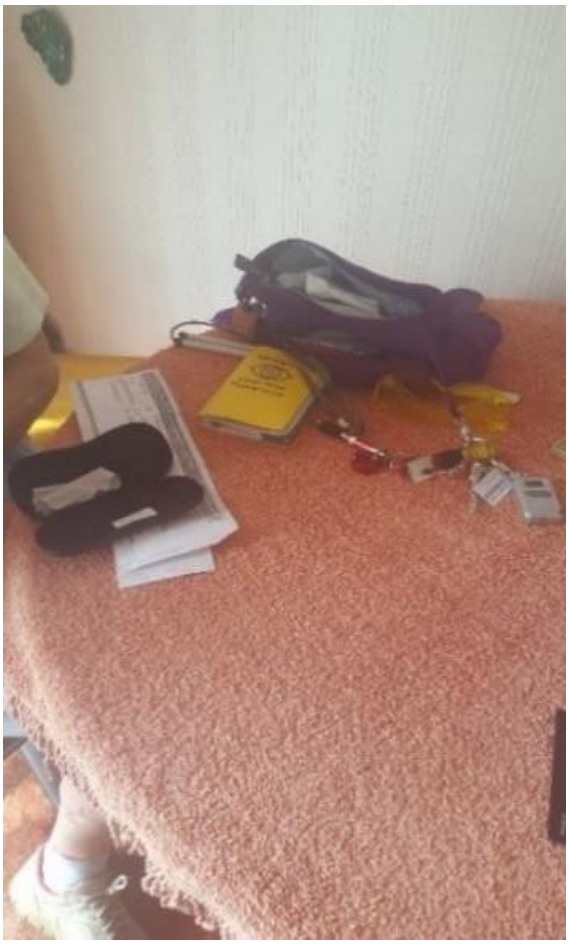


Photo 7.3 Handbag as *'...my life is muddled.'* (DWC13)

As with the IDEAL and primary cohort of DWC, this DWC was typical in profile of DWC (i.e. white, British, female), but was unique as one of only two DWC in the primary cohort who were in their late seventies. These DWC represented the predicted increase of aging working carers (TUC, 2010).

Other DWC similarly highlighted the difficulties associated with managing multiple responsibilities, where kitchen scales were selected to represent the desired 'balance' (See Photo 7.4) between work and care.

Photo 7.4 Scales as constantly weighing the priority of day-to-day activities (DWC12)

As the participant explained:

'[…] everything is a bit of a balancing act really. You know on one side you've got your family and on the other side you've got the person you're caring for.' (DWC12)

For many DWC (17 out of 24), one negative impact of the overlap between work and care~~,~~ was on the evaporation of available time in the day. The conflicting demands of combined work and caregiving meant little time to fully commit to work and caregiving tasks, or to nurture their own interests. In the following extract, the DWC who had multiple roles, a male in his late seventies and caring for his wife with dementia, explained how time restrictions had impacted his ability to protect his physical wellbeing:

'...I used to go swimming regularly. I can't do that now 'cause it means going to [town further away]. I used to go on much longer walks much more regularly, which I now don't do because I haven't got the time to do it. So it's a time related thing….' (DWC9).

These objects and the voice of DWC challenged the theory of role balance (i.e. work and life reconciliation - Marks & McDermid, 1996), whereby the combination of work and care roles led to inter-role conflict (i.e. Merton, 1949; 1957). It seemed that the impact of balancing work, care, and life could not be simplified from how work impacts on life or vice versa. A constant weighing up between the management of work, care, and life, was required to sustain wellbeing and prevent break down occurring in the day-to-day lived experience of the DWC.

7.6.2 Triple-duty caregiving responsibilities

Additionally, further complications and challenges on managing work, care, and life are found on those who have multiple caring roles. A few (4 out of 24) DWC interviewed had triple-duty caregiving responsibilities (i.e. both child care and elder care i.e. DePasquale et al., 2016). Although the number was very small in this study, arguably the population figures are likely to be higher due to accelerated population aging (DePasquale et al., 2016) and reproductive ageing (Cook & Nelson, 2011). Such multiple caregiving responsibilities are an additional burden, contributing to the feeling of exhaustion, and reducing the ability for DWC to attend to their own needs. As one DWC explained, the responsibility of three roles~~,~~ meant there was little time for respite activities:

'I don't have enough time to do anything. I don't have any support […]. So trying to juggle that, and the competing needs of like, mum and my daughter and my job...and studying as well […]. Yeah, there just wasn't any respite at all…' (DWC24).

As with other findings with DNWC (i.e. Rosness et al., 2011), additional caregiving responsibilities (i.e. childcare) contributed to increased strain for DWC. Additional caregiving duties and economic status was not explored in the quantitative strand of this thesis. Therefore, these findings contribute more to what is known about the challenges facing those DWC with additional caregiving responsibilities.

7.6.3 Overall wellbeing

The DWC interviewed elaborated on the impact of combining work and care on their overall wellbeing, which was based on their mental/emotional health, physical health, social functioning, everyday functioning, and economic status. Over half of DWC (15 out of 24) for instance, referred to the impact of sustaining both roles on their mental and emotional wellbeing. In some cases, mental health suffered more than physical health. A few DWC (3 out of 24) described the mental impact of the working role~~,~~ on their ability to sufficiently carry out caregiving duties. Some DWC (7 out of 24) referred to the impact of caregiving on their role at work, which often created worry and guilt about leaving the PwD unattended. In the following extract, one DWC highlighted the mental and emotional impact of working and providing care:

'*[Care and work] just makes me feel very depressed really, because I think, because I don't have a life, and so I feel really old before my time.'* (DWC24)

In this case, the DWC was white, British, the daughter of the PwD, a single parent, and the primary carer for her mother. This DWC was atypical of most DWC in the larger and primary cohort, as a much younger carer at forty years old. Although her mother was in a care home, combining work and care was particularly difficult for this DWC, who was also managing her studies on top of caring, working as a Clinical Support Worker, and performing childcare duties. This role overload left little time for a social life, making her potentially vulnerable to depression. It could be argued then, that more support with caregiving duties is essential so that DWC can maintain work with caregiving duties, and professional training associated with career progression.

Over half of DWC (16 out of 24), explained how the time spent on work and care duties impacted their physical health, limiting their motivation to keep fit and healthy. For some DWC (4 out of 24), exhaustion at work depleted some of the energy available for caregiving. Other DWC (4 out of 24) referred to the physical impact of caregiving on the working role. In another extract, one DWC explained the physical health risks associated with role overload, which were often associated with 'tiredness' and 'exhaustion':

'I think that the feeling of constantly juggling people who all need my attention at once, making sure that everybody gets the attention that they need, getting tired […] it's a strain at times.' (DWC21)

In interviews, some DWC (7 out of 24) referred to the impact of juggling work and care on their social relationships. For a few DWC (2 out of 24), caregiving impacted their ability to socially integrate at work, or with friends. For these DWC, social life was impaired by the requirements of care and work duties, deterring the opportunity for DWC to achieve respite by meeting with friends or colleagues. The extra responsibilities associated with balancing work and care in these cases, meant that little time was left for social interaction, as one DWC highlights:

'I don't go out so much really. [It is] more of an effort to go out.' (DWC3)

My quantitative findings also show a significant relationship between strain-based family-to-work conflict and the cognitive function of DWC (Chapter 6.5). The interviews further found that the impact on cognitive function of combining work and care was another concern in the everyday functioning of many DWC. Interestingly, the association was only observed for everyday cognitive failures, and did not emerge on the measure that looked specifically at attention. Nevertheless, for over half of DWC (19 out of 24), the combination of work and care commitments left them with the perception of impaired memory and attention. In some cases (6 out of 24), the impact of caregiving on everyday functioning meant that workplace performance was poor, and responsibilities at home are neglected when work interferes with care (2 out of 24). The following extract emphasises family-to-work strains on alertness in the working role:

'...sadly work and caring has a very negative effect on my attention span. My short-term memory […] I find that I have to just write reminders down to myself, and I have to really plan my [teaching] lessons even more carefully […] it eases a huge amount of energy because I start to forget things more easily now because of both roles.' (DWC17)

The financial and career development impact of combining work and care was referred to by several (8 out of 24) DWC. These DWC highlighted the burden of caregiving on their career prospects and their earnings. The minimal rates associated with

CA and income restrictions for instance, prevented DWC from providing full-time care and working more hours. For some of these DWC (7 out of 24), providing care impaired their ability to progress at work. For a few DWC (2 out of 24), placing the PwD into care also meant selling the PwD's assets (i.e. home, savings) to fund expensive care home fees; this was an additional emotional and financial strain. The following DWC explained the detrimental impact of caregiving on her career:

[…] this isn't...what I wanted out of life, and when I look at my career my research would be going a lot better if I didn't have to do this, and I would be able to go to that symposium or that conference, or give that talk, or do all that stuff […] that I can't...do' (DWC1)

In other cases, DWC left thriving careers and substantial incomes, to seek careers which would accommodate caregiving duties. This meant that the financial position of some DWC was precarious. A DWC in his mid-fifties who changed his job as a surety underwriter to a bus driver, due to caring for his father with dementia, described how becoming a dementia carer had meant a dramatic decrease in his career ambitions, household income, and pension:

'[Combining work and care] has meant an enormous change and sacrifice on my part. For instance, I've actually given up my thriving career of 30 years. Also as well, I've given up […] my pension with my previous employer, and I've given up a substantial salary in order to sort of downsize and try and find a balance, and that balance has resulted in me doing a less demanding job, a completely different career change and a vast reduction in…income to the family budget.' (DWC12).

For self-employed DWC, economic stability was less certain. One DWC expressed his concern regarding the lack of support and policy protection among those with their own businesses:

'...when you've got a business, the money's never gonna be equal week to week […] then there's the expenses. Quite often when you've taken away all the things you've had to pay for and everything else, there's maybe not much profit that's actually being earned […] so you might be able to say 'well I might pay myself a wage, maybe that's only the amount

that they're gonna let me have, but then what do I do with the excess? […].' A lot of these questions aren't answered by the government.' (DWC20)

7.6.4 Summary: Work, care, and life conflict

As highlighted in the challenges theoretical framework, inter-role conflict occurs when various social arrangements clash. For DWC interviewed, the combination of work and care had a detrimental impact on the time that they could devote to their personal lives, and their ability to fully engage in both work and caregiving roles. The enhanced information provided by DWC interviewed expands the quantitative findings, where time-based and strain-based interference with work were the main source of work-life conflict for the primary cohort of DWC (see Chapter 6.5).

Role overload and inter-role conflict also have negative consequences for overall wellbeing. For several DWC, the strain of juggling work and care meant that mental/emotional wellbeing, physical health, and social wellbeing were compromised among DWC. For some DWC, this impaired their ability to carry out work and/or caregiving roles adequately. As described in Chapter 2.6, the combination of work and care has a detrimental impact on the mental (i.e. Nurfatihah et al., 2013; Wang et al., 2013; Alpass et al., 2017), physical (Nurfatihah et al., 2013; Kimura et al., 2015) and social functioning (Nurfatihah et al., 2013) of DWC. The economic and professional conflict of family-to-work interference also meant that DWC were restricted to fewer working hours and limited progression in their careers. Concerns about future economic security was related to the impact of compromised working hours on pension contributions. The quantitative analyses demonstrated that DWC experienced poorer wellbeing outcomes associated with strain-based family-to-work conflict only, but strain-based work-to-family conflict did not reach significance.

For the majority of DWC interviewed, the price of combining work and care was reported to be on cognitive performance (i.e. memory and attention) and impacted alertness in both roles. While these findings are supported by research which has found an impact of care on workplace performance in non-dementia working carers (i.e. Phillips, 1995; Gignac et al., 1996), this finding was not statistically significant in the quantitative analyses of DWC in the primary cohort. Therefore, qualitative content analyses exposed a contradiction between the perception of the DWC and their own responses to a questionnaire that posed specific questions about everyday memory slips and errors. A more in depth set of measures are needed to resolve this contradiction. By

combining qualitative and quantitative data this thesis has enhanced the limited findings of work, care, and life conflicts for DWC.

7.7 Outstanding support needs

As argued by Twiggs (1989) (see Chapter 2.3), the social support needs of DWC and the PwD they care for were further emphasized by the participants interviewed. All DWC referred to aspects of support which were missing from the social care system, and in the workplace. Several areas of support were identified and included the reliance of formal and informal care for PwD, the reliance of care professionals for DWC, and dissatisfaction with the social care and health care system.

7.7.1 The outstanding formal and informal care support for people with dementia

In semi-structured interviews, DWC highlighted the need for formal sources of support for PwD, including integrated care services, advice and information with dementia care, greater strategies to improve community awareness of dementia, and less indifference towards DWC by health care services.

The complex health and social care needs for PwD are often met by multi-agencies. However, there is evidence on the lack of integrated support in dementia care which results in greater efforts by DWC who are faced with additional care co- ordination work. Some DWC (8 out of 24) described the confusion created by a lack of co-ordination between organisations that provide respite care and other services for PwD. Many of these DWC also expressed frustration when dealing with multiple agencies that act in isolation. This led some of these DWC to recommend more '*joined-up thinking'.* In the following extract, one DWC explained the problems associated with a care package that consists of agencies who serve different functions:

'*…my main problem is losing track of who's who. There's Carers Support, who give me a call once a month…. and we had somebody from […] mental health assessment I think they're called […] and now I'm meeting somebody from Alzheimer's Society once a month […] and you know, all the thing around district nurse, occupational therapist, social worker…*' (DWC7)

The availability of information and guidance on dementia care was also an ongoing concern for DWC. These DWC (9 out of 24) referred to the need for more transparent information and advice on the available services in dementia care. In some cases, DWC were unclear about the support available to them. The same DWC felt that there should be more personal training for dementia family carers. This DWC explained that transparent information, advice and individual caregiving training would improve their caregiving skills:

'…I did speak to the occupational therapist about [any other support that could help me with caring] but didn't really unfortunately […] get an answer. […] I'd love to have just somebody come in for a couple of hours to train me in stuff […] you've got a wife who's quite physically disabled, and I do lift her out of bed and move, manoeuvre her around, those type of things, and things around sensitive issues like hygiene […]. There are some things that don't come naturally to me at all [laughs], and it's even harder to ask the question, you know - 'how do you help someone off a commode?''(DWC7)

As another DWC noted however, individual guidance relating to dementia care, can be difficult to obtain:

'...I could do with some help and advice on it [dementia care], but […] I wouldn't even know actually who to call, but I feel it's like…there's a lack of a real caring system for carers out there.' (DWC21).

Many DWC (15 out of 24) suggested that there should be better strategies to enable the community and public services to develop more awareness about dementia. Some DWC pointed out that greater community awareness would reduce the 'fear' associated with the disease and improve care in their towns and cities. In the following extract, one DWC suggested that while positive steps are being made to improve dementia awareness in the community, still more effort was required to remove the stigma associated with the disease:

'…Fear of the unknown is what pushes people away, and it's the same with all of us I think, but it's particularly bad with this [dementia] 'cause you can't see a physical disability until it's much more advanced. […] I think the only way you can overcome that

is educate people and try and make them a little bit more sympathetic. You can't force them, but you can just make them aware, and I think that's started, but I don't think it's anywhere near as far as it needs to be.' (DWC23)

In this case, the DWC was one of the few male DWC, in his mid-sixties, self-employed, and caring for his wife in the severe stages of dementia.

Over half of DWC interviewed (13 out of 24), voiced their frustrations at the management requirements of formal carers with caregiving tasks. Many DWC for instance, felt that the guidance required by home carers increased the amount of time that they spend on caregiving tasks to 'train' formal carers in the specific care needs of the PwD. Therefore, in many cases, respite support by home carers served the opposite function by generating more work, as highlighted by one DWC:

'[…] I find that obviously the carers need to be left notes and instructions for instance you know, if my mum's on a good day or a bad day […] if she's had an instance of incontinence you know, what she's had for breakfast...and that takes a heck of a lot more management than I would have imagined and obviously involves me in more paperwork.' (DWC17)

In other cases, DWC expressed frustration at the indifference towards them by the health service, particularly by General Practitioners and helplines. In the following dialogue, one DWC discussed the lack of support from care professionals, and described several services which were unaccommodating during a crisis:

Researcher: '*[…] Could you discuss any support which assists you with combining work and care? That could be financial, external support, family support, anything you can think of.*

DWC: *'Mmm family support?'*

Researcher: *'Or financial…'*

DWC: *'Or financial support yeah?'*

Researcher: *'Or even external if you get anyone coming in from the outside?'*

DWC: *'Mmm yeah, yeah, yeah, that would be good but…[I] don't.'*

Researcher: *'[…] you don't get outside like Alzheimer's support or carers […]?'*

DWC: *'No. No we don't. They just give you leaflet [they say] 'read', and that is it. Once he [PwD] was in a bad way. He wasn't eating. I tried calling the GP […] to say 'this is what is happening'. They say 'you call the mental health. You try calling them'. The phone wasn't going through. So what is the point? […] Everything you just have to do it on your own. There's no help, which is not good.'* (DWC8)

In this case the DWC was black, African, in her early forties, working in a low-income role, and the primary carer for her husband with dementia, with little support from extended family who live further away. In comparison to other DWC who are white, British, she is the only ethnic minority in the primary cohort, which is also typical of the over-representation of white, British DWC and DNWC in the larger cohort and among larger numbers of Caucasian carers in research generally (Morrison et al., 2016).

The delivery of care reviews by health professionals was also referred to by 7 out of 24 DWC. Some DWC described the care review as a checklist procedure, rather than a systematic evaluation of wellbeing and caregiving support needs. One DWC for example, complained that care reviews were improperly conducted because professional resources were low:

'…when we go back and see the consultant, it's a checklist routine. […] obviously they've got empathy, but they're under a time pressure, and all they wanna do is just see how far we've got. You need to be more aligned with the needs of the individual, and that all takes time, and they haven't got the time. So…this is only gonna get more difficult as time moves on, because more and more people are gonna suffer from [dementia], and if you don't address that, it's gonna be overwhelmed. Both from a financial point of view, and a resource point of view […].' (DWC23).

The challenges framework in Chapter 3.3 suggests that the background support structures of DWC play a role in whether DWC will experience conflict between multiple roles. Individual guidance was one concern of DWC, who stressed that more advice about dementia caregiving was necessary, as well as greater community awareness and sympathy towards dementia generally. Related to this, was the detachment among

professional agencies for PwD, and health care professionals, with an absence of co-ordination between organisations, and a lack of sympathy towards the caregiving support needs of DWC. These findings generate more details about the limited resources in dementia care support and are reflected in previous research (i.e. Arksey et al., 2005; Yeandle et al., 2007; Arksey & Glendinning, 2008; Milne et al., 2013) which has identified that accessing information and advice, good-quality social-care services, are still an ongoing concern for carers.

7.7.2 The outstanding support needs for dementia working carers

While previous research has highlighted the formal and informal support needs of DWC with dementia care, the outstanding support needs of DWC themselves have not been interrogated. This has further raised the concern of carers as being seen as co-partners in care while their own needs and rights are being overlooked. Nearly all DWC (22 out of
24) interviewed, further referred to issues which were centred on: respite care; emotional support; finance; caregiving support in the workplace. Many DWC (18 out of 24) referred to formal support in terms of professional respite care. This included home care and day care services. Formal respite support for PwD was recognised as something which would enable DWC to better reconcile work and care. For other DWC (7 out of 24), the informal PwD respite support received from family was unsatisfactory. The following DWC explained how additional respite care for personal caregiving tasks (i.e. toileting) would reduce the strain of caregiving and improve the carer-dyad relationship:

'…if someone else was doing the really horrible jobs, like dealing with all the faeces and urine and whatever, then I could do the fun things like take my nan out for a drive and we'll have a sing song […]. Maybe take her out just along the pier or something, and I'm so busy doing everything else I don't get to do the fun bits anymore. It's just the miserable bits.' (DWC10)

The need for more respite care for the PwD from family was particularly common for DWC with siblings, as one DWC explained:

'[my mother-in-law's] other daughter could potentially do more, but then they've got their own family and that…' (DWC2)

In 13 out of 24 cases, DWC described the need for personal services, such as support groups for dementia carers and one-to-one counselling. The following quote is taken from one DWC who felt that more dementia support groups are required:

'More support groups, dementia cafes, so people can meet folks in similar situations.' (DWC11)

However, cuts to social care funding mean that some DWCs felt that more personalised one-to-one support would be difficult to obtain:

'I suspect counselling would be a good idea […] oh there's no funding available for it is there […] unless I get really depressed or something and cry constantly, then I'm not gonna tick boxes to go to tops of waiting lists or anything you know.' (DWC1)

Many carers (15 out of 24) referred to the financial burden of providing care. The following DWC suggested that tax breaks and increasing CA, would go some way to compensate for lost revenue caused by reduced working hours:

'Tax breaks would be good. Anything that would take off the financial burden, and financial (burden) isn't limited to the cost of care. It's the lack of ability to earn money because you're not being able to go to work. So something that would allow you to earn money […] or get more for the money that you are actually earning.'(DWC2)

For some DWC, increasing CA would similarly compensate for a loss in income. In the following extract, one DWC described the financial constraints he had endured due to the restrictions associated with CA and the cap on working hours:

'[…] because carers allowance at £62.70 per week is well below living wage, and even when they allow you to earn up to £118 a week, that's still again well below […] they should at least expand the amount that you can earn in a given week […] you should actually be able to be setting some money aside for your pension and things like this. I feel that's a duty, a moral duty for them really, that they allow you to have more money. Not restrict it so much.' (DWC20)

Another DWC highlighted the insufficiency of the UK model of care, which, in the case of limited funds, is associated with stripping assets belonging to the PwD, to pay for care home fees. This DWC suggested that greater changes in English social care policies, should be modelled on the German model of care, where future care needs for all citizens are secured through a nominal amount of tax contributions (Glendinning & Wills, 2018). The German model of social care therefore, was recommended as a long-term solution to the financial burden of dementia care:

'All politicians are constantly banging on about the pensioner having to sell their property […]. I would have thought, personally, the best model would be that from the time someone goes out to work until the time they retire, they pay a small nominal amount each month or week out of their pay packet. This goes into adult social care […] like Germany, is ring-fenced completely, and no government is allowed to touch that for any other purposes. So that there will be people paying in that will never need social care, but there will be those that will […].' (DWC12)

Further frustrations were directed at the inflexibility of the personal budget. In the following example, one DWC complained that the personal budget should be more flexible in supporting caregiving costs:

'[…] I was offered the personal budget. They said 'you can have whatever you want. Do you want a computer or something?'. I said 'I don't want a computer, I've got one'. 'Well do you want a kindle?'. 'I don't want a kindle, I've got one'.' […] I said 'I tell you what though' […] 'I could have some money to help pay for […] all the diesel and the wear and tear on the car'. '[They said] No, no, I can't do that.' (DWC12)

Almost half of DWC (11 out of 24) expressed concern about the lack of support in the workplace. Fewer DWC than expected however, referred to workplace support. This may be indicative of the greater number of participants in this study who own their own business (5 out of 24) or had already sought out other flexible positions which would adapt around their caregiving responsibilities. For these DWC, work-life reconciliation would be improved if employers were more accommodating of caregiving responsibilities, by being more creative with schedule flexibility:

'[…] there are ways in which [employers] can help people, without it costing [them] a lot, and [they] get back the loyalty, because it's not that [their] staff are going to be …less available, it's just that they need that flexibility, you know.' (DWC19)

Some DWC (4 out of 24) highlighted their concerns about the lack of support from management and colleagues. In the following extract, one DWC communicated her fear of losing her job due to a lack of empathy from her employer:

'[…] I think sometimes initially they'd [employer] been a bit non-understanding of quite what I'm going through, and I try to keep it very separate from my job because I […] don't wanna lose my job […].' (DWC17)

Other DWC (6 out of 24) were unclear about their workplace policies, thus demonstrating the poor clarification of carer's rights in the workplace by employers and the government:

'I don't know what the policy is to be honest'. (DWC10)

'…I don't know enough about the policy making, whether there is safeguard[ing] in place for people that find themselves becoming [carers] and whether there can be request to leave, or maybe unpaid amount of time to come out of the workplace, but guarantee your work to come in […]' (DWC14)

For a few DWC (2 out of 24) being self-employed meant that the professional impact of combining work and care felt even more isolating, since there were no policies to protect their work-life reconciliation:

'…there doesn't seem to be any support...for both actually – self-funders or if you're self-employed.' (DWC10)

In this case, the DWC was typical of DWC in the larger and primary cohort, as a female, white, British carer. However, this DWC was younger (forty-one) than most DWC in the sample (mean age being 56.37), in a low-income role, and was providing care for both grandparents with dementia.

7.7.3 Summary: Outstanding support needs

As with other studies with dementia carers (i.e. Kjällman-Alm et al., 2013; Quinn et al., 2015; Johannessen et al., 2016; Alves et al., 2017; Hwang et al., 2017; Wawrzicznyet al 2017; Anderson & White, 2018; McCabe et al., 2018), DWC highlighted the need for more formal and informal respite care resources. For many DWC, the challenges to sustaining work-life reconciliation were associated with the limited respite care that the PwD received. In accordance with the Care Act recommendations, the preservation of wellbeing was also important for DWC. These findings enhance the limited knowledge of the emotional support needs of DWC and highlight a gap in the quantitative analyses, which did not directly address the outstanding support needs of DWC. While research has demonstrated that emotional support reduces feelings of isolation for working carers (SCIE, 2018), many DWC also outlined that they need better access to emotional support, such as one-to-one counselling and dementia support groups. The need for financial assistance was also prevalent among many DWC, who described the restrictions associated with the receipt of CA and enforced income caps. Related to financial assistance was the need for more choice in how DWC spend their personal budget. In line with other findings (HMG, 2014; Hoff et al., 2014; Principi et al., 2014; Depasquale et al., 2016), several DWC further explained that work-life reconciliation would be better supported if employers and managers were more empathic and accommodating of their caregiving role. As supported by related research (EfC, 2011), some DWC were unaware of their employer's policies towards working carers, thus highlighting a discrepancy between carer's rights in the workplace and miscommunication of employer policies by organisations.

7.8 Discussion

Building on my quantitative findings, this chapter, based on interviews and artifact elicitation, explored the challenges to sustainable work-life reconciliation that might impact on the poorer wellbeing of DWC. The emergent themes from this chapter further qualify the early quantitative findings relevant to the challenges to work-life reconciliation (i.e. caregiving strain, and conflict between work and life) in Chapter 6.6 and contribute new insights beyond those explored in previous

DWC research (i.e. the bidirectional impact of work and life, and the outstanding needs of PwD and DWC). However, it is also acknowledged that studies which use triangulation designs can also result in several areas of concern which include ascertaining the contribution of each source during synthesis (Mitchell, 1986; Sandelowski, 2003), with both methodologies often incorporating quite different aesthetic and technical criteria (Sandelowski, 2003). Furthermore, Symonds and Gorard (2009) highlighted that while larger sample sizes (i.e. quantitative data) are considered more representative of a population, smaller samples in qualitative findings are considered 'non-representative' resulting in subjective generalisations. Therefore, while qualitative findings 'enhance' quantitative data, Creswell and Plano Clark (2007) have similarly highlighted that triangulation studies serve to support the limitations of both methods of data collection and comparison. Symonds and Gorard (2009), however, emphasised that the issue of representing a fixed population is dependent on the research topic, and that the quality of generalisations is not necessarily restricted to a specific sample size. In this study, differences between DWC in the IDEAL study versus those DWC in the primary sample extended beyond variations in sample size. In chapter 6.5, these differences were discussed and related to differences in educational attainment and greater situational management, but also poorer overall wellbeing, and lower caregiving competence scores; these differences were attributed to DWC in the primary sample caring for care recipients with higher dependency needs. Heale and Forbes (2013) acknowledged that while the results may be divergent or complementary, the main objective of such studies is to promote a more comprehensive understanding of a phenomenon to enhance the rigour of research. The complementary findings reported here support this position.

In this study, the DWC reported that the negative caregiving experience (indexed as caregiving burden) was heightened by inter-role conflicts that left little available time for respite from work, caregiving, and other family duties. The reasons that DWC felt less confidence in their competence and coping abilities in the caregiving role than DNWC, then, might relate to overlap between work, care, and life responsibilities, which meant that overall wellbeing was compromised. Furthermore, the outstanding support needs of PwD were centred on the lack of assistance with care from family and professional agencies. Professional caregiving and support services for PwD were often poorly received by DWC, who

highlighted the unsuitability of care professionals and care workers as well as the lack of co-ordination between multiple dementia care agencies. Those outstanding support needs for PwD added additional work and burden onto the DWC role. In addition, DWC were not always receiving sufficient support to sustain their employment and caring roles. For example, professionals who do not actively listen to DWC might contribute to the individual needs of DWC being neglected. Relating to this was the need for more emotional support and care training, and more workplace support (i.e. flexibility at work and understanding of DWC in the workplace).

The lack of financial remuneration for caregiving, and the restrictions on weekly incomes were perceived to impact on the current economic wellbeing of DWC and beyond. DWC highlighted that financial issues for carers would be alleviated somewhat by introducing tax breaks and increasing CA. However, longer-term planning on behalf of policy makers was also recommended. Therefore, while these findings provide more understanding of the threats to work-life reconciliation for DWC, the recommendations put forward by DWC suggest that major improvements in social care and workplace policies are necessary to maximise the sustainability of work and care responsibilities for DWC.

Chapter 8:

The experience of the everyday life of dementia working carers: Sustaining work-life reconciliation

8.1 Introduction

To gain more insight into the quantitative findings on sustainable wellbeing and work-life reconciliation among DWC, this chapter draws on the experience of DWC in achieving sustainable work and life balance. Firstly, I reflect on the background literature in Chapter 2 and the theoretical framework in Chapter 3.3, which is relevant to how DWC might counteract the strain of various role-set demands to sustain work-life reconciliation. In this qualitative analysis, I considered the quantitative findings (Chapters 4-6) which related to the psychological and personal resources employed by the full and primary cohort of DWC, to further explain the qualitative themes of sustained work-life reconciliation in this primary cohort. For the final section of this chapter, I form an overall conclusion of the qualitative findings relating to the strategies used to sustain work-life balance among the primary sample of DWC.

8.2 Sustainable work-life reconciliation among dementia working carers: What we (do not) know so far

The sustainability theoretical framework highlighted in Chapter 3.3, describes how role-set theory is concerned with the social mechanisms which counteract the strains of role-set demands (Merton, 1949, 1957). Within this framework, resilience is a key individual characteristic for sustaining wellbeing (Abolghasemi & Taklavi Varaniyab, 2010; Souri & Hasanirad, 2011; Liu et al., 2012; He et al., 2013; Smith & Hollinger-Smith, 2015), mediated by psychological resources and caregiving experience. Resilience refers to the ability of individuals to face and overcome adversity (Luthar et al., 2000; Campbell-Sills et al., 2007), and the adaptative strategies they use to cope with discomfort and adversity (Tugade & Fredrickson, 2004; Taormina, 2015). As discussed in the 'sustainability' framework, problem-focused coping strategies are reported to be superior for stress-management and are based on strategies associated with: problem- solving; time-management; obtaining instrumental support (McLeod, 2009). Emotion-

focused coping strategies are similarly associated with positive coping strategies such as: distraction; prayer; meditation i.e. mindfulness (Lazarus & Alfert, 1964). Previous research (Donnellan et al., 2015) has confirmed that support from family, friends, and professional respite care also improves dementia carers' resilience for coping effectively with caregiving demands. The positive association of resilience with eudaimonic wellbeing has been well-founded (Souri & Hasanirad, 2011; He et al., 2013; Smith & Hollinger-Smith, 2015), with regard to life meaning and an authentic sense of one's own life (Ryan et al., 2008; Di Fabio & Palazzeschi, 2015).

The few studies which have focused on the employment status of DWC (Wang et al., 2011; Wang et al., 2013; Alpass et al., 2017) have found largely negative outcomes associated with combining work and care (i.e. role strain, work-life conflict and poor QoL). Johannessen et al. (2016) also found that resilience and positive coping strategies were important for those who combined work and caring. Wang and colleagues (2013), however, found that higher preparedness for caregiving demands was associated with decreased role strain, when DWC experienced work-care conflict. These findings imply that DWC coping strategies are particularly significant for sustaining wellbeing. Söderhamn et al. (2013) also found that when respite care was in place, DWC gained a feeling of enthusiasm and freedom, and a good conscience. At work, flexibility and part-time employment have also been associated with fewer depressive symptoms among DWC (Wang et al., 2011). Research with DNWC (Bristow et al., 2008; Pattanayak et al., 2011; Alvira et al., 2015; Raivio et al., 2015), DWC (Söderhamn et al., 2013) and carers of elderly people with other care needs (Courtin et al., 2014) also suggests that respite caregiving support, and emotional and instrumental support improve sustainability. The quantitative analyses reported in this thesis further demonstrate that DWC have greater psychological resources (i.e. higher self-efficacy in Chapter 4.3 and self-esteem in Chapter 5.3), a more positive caregiving experience (i.e. reduced relative stress in Chapter 5.3, and greater situational management in Chapter 4.4), and more satisfaction with personal relationships than DNWC, with both higher self-esteem and reduced relative stress being associated with a better QoL (Chapter 5.3). Within the primary cohort, a more positive caregiving experience (i.e. lower caregiving burden, less role captivity, and a greater sense of caregiving competence), and lower time-based and strain-based family-to-work conflict were associated with better wellbeing outcomes (see Chapter 6.5).

Based on the theoretical framework of sustainability, previous research with DWC does not detail the types of coping strategies DWC use to balance work and care.

Furthermore, a one-way impact of conflict has been described (i.e. life-work conflict), based on caregiving burden, as opposed to the more nuanced analysis of bidirectional influence of work-to-life and life-to-work benefits. We also know very little about how the support utilised by DWC at work and home assists the work-life balance. Drawing on the theoretical framework of sustainability and the background literature, I address these clear knowledge gaps in the research findings reported below, to explore how DWC contextualise the experience of sustainable work and life balance.

8.3 Methodology

Twenty-four semi-structured interviews are conducted with the primary cohort of DWC, and centre on an artifact selected by the interviewee to represent the work-life balance. For further information of the methodology see Ch 3.7.3, Ch 3.8.3 and Ch 7.3. The following overarching question explores 'sustainability':

- How do you as a DWC achieve a sustainable balance between work and care?

8.4 Results

Twenty-two out of twenty-four artifacts selected by DWC represented how 'balance' between work and care was achieved. One artifact (i.e. handbag) represented the challenges of work-life balance and sustainable work-life balance, and two artifacts (i.e. make-up and carers magazine) were selected by one DWC who struggled to select one artifact, to represent the challenges of work-life balance and sustainable work-life balance. Emerging themes, related to the self-management strategies used by DWC to achieve work-life balance, and consisted of: organisational skills; respite strategies; transferable/transformative skills (between work and caregiving); support (at home and work); bond (caregiving relationship). The artifacts selected by DWC were categorised under the emergent themes and are presented in Table 8.1.

Table 8.1 Sustainability represented by the artifacts, demonstrated by themes

Artifact	Theme 1: Organisational skills	Theme 2: Respite strategies	Theme 3: Support at home and work	Theme 4: Bond
Tablet (personal organiser)/iPad	✓✓			
Fountain pen	✓			
Filofax	✓			
Mobile phone (x2)			✓✓✓	
Handbag	✓			
Keyring		✓		
Car (driving)		✓		
Invoice (formal care support)			✓	
Wedding ring				✓
'Prosecco o' clock' LED sign				✓
Rock/nodule - study		✓		
Yoga mat/Swimming costume		✓		
Whiteboard	✓			
CD		✓		
Potato peeler (distraction technique)	✓			
Photograph (grand-children)			✓	
Horse		✓		
Reading App		✓		
Make-up		✓		

Using qualitative content analysis with the aggregated qualitative dataset on the topic of 'sustainability' explored in interview transcripts, five themes emerged: a) organisational skills; b) respite strategies; c) transferable skills between work and caregiving; d) support from home and work; e) bonded relationship between DWC and PwD.

8.5 Organisational skills

DWC interviewees elaborated on the strategies they used to combine work and care. Eighteen out of twenty-four DWC stressed the importance of organisational skills as a way to manage their available time more efficiently. Seven objects selected by DWC were chosen because of their organisational properties, and enabled DWC to 'keep on

top' of the multiple responsibilities of managing caregiving, employment and family life. To remain organised, DWC emphasised the importance of synchronised schedules (5 out of 24) with co-caring partners (i.e. spouses and adult children). The following DWC selected a tablet (see Photo 8.1) to demonstrate how she synchronised schedules associated with caregiving, childcare, and work, with her co-caring spouse:

'[…] I love my tablet. It goes everywhere with me […] my tablet has enabled me to synchronise my work diary with my diary that I share with my husband, which enables me to achieve the ridiculous list of things I'm supposed to achieve because… I kept double booking myself, so that because with the caring commitments and with my children, and work, and study, I couldn't keep my commitments in my head, and I kept muddling up and not turning up to stuff, and there's that synchronisation there that's enabled me to be where I'm supposed to be, and the fact that I can set reminders so that my phone beeps at me to say 'okay'….'' (DWC1)

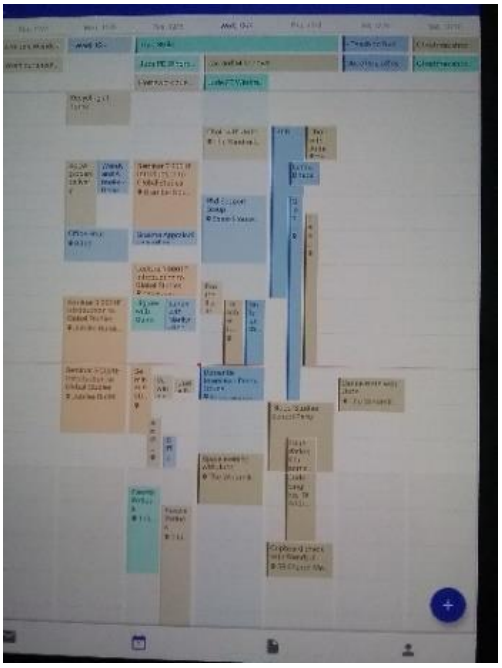


Photo 8.1 Tablet as synchronising a busy schedule with co-caring partner (DWC1)

Based on the profile of DWC in the larger cohort profile, this DWC was representative of most DWC in the full sample. In this case, the DWC was white, British, in her late forties, and besides dementia care, was combining teaching with studying, and

home-schooling her son with special needs. Therefore, having instant access to internet-enabled methods of organisation (i.e. mobile phones, tablets) was especially important to this DWC when weekly schedules had to be synchronised and continuously updated with care partners.

Other artifacts included filofaxes, diaries, and a whiteboard planner (see Photo 8.2), which enabled schedules to be recorded and updated for roles relevant to work, care and other duties. In the following example, the DWC explained how a whiteboard planner reduced worry, by enabling her to write important reminders for her mother with dementia, while she was at work:

'I've chosen, my little whiteboard and eraser and marker pen, because this is how I would leave a message, a reassuring message for my mother when I have to be out of the house, and the time that I'll be back, the time that a carer would be here, and possibly a reminder for her to drink, drink some water. It'll also have the date on it so that you know, at a glance, she can if she wants (to), remember the date. The other reason I've chosen it is because I work as an adult ed(ucation), tutor, and so of course whiteboards on a larger scale than this, are very much part of my working life. So, for me, the object is the perfect illustration of the work-life balance that I'm having at the moment.' (DWC17).

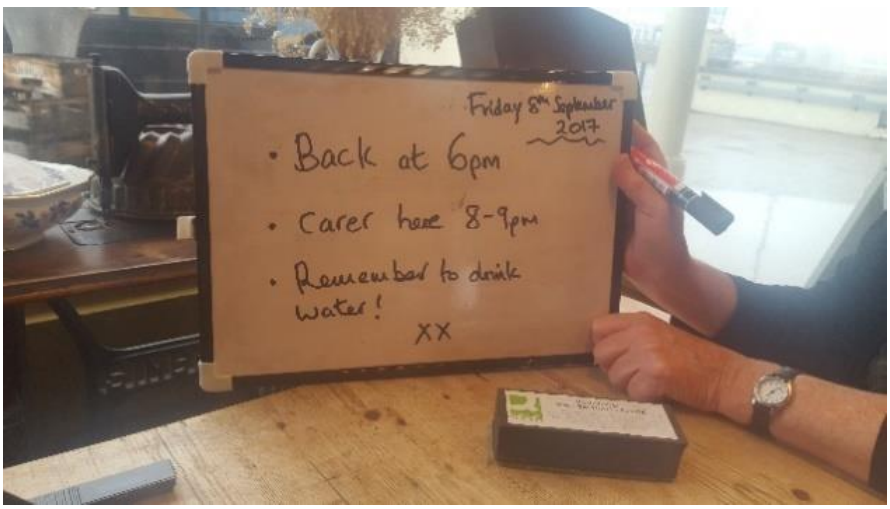


Photo 8.2 Whiteboard as a mediator to engage with care while being away (DWC17)

In this instance, the DWC typically represented DWC in the IDEAL cohort. This DWC was white, British and in her mid-fifties.

Other areas of organisation that support sustained work-life balance, were related to making the most efficient use of down time with work-related micro-tasks on electronic devices (2 out of 24). Below, one DWC emphasised how work-related tasks were performed on an iPad and mobile phone during the available time between work and caregiving:

'...mum did a course up at [hospital]. […] and that was hysterical because I used to go there and do work. I'd sit in [hospital] [laughs] with an iPad, so like trying to get some work done […] she was there for an hour so I can get a lot done, but I'd be sitting there phoning people and everything...' (DWC6).

8.5.1 Summary: Organisational skills

The quantitative findings in Chapter 6.5 demonstrate that DWC with lower time-based family-to-work conflict had better wellbeing outcomes. Based on the theoretical framework of sustainability, time-management is a common feature adopted in problem-focused coping strategies. The artifacts selected by the interviewees included several electronic and manual methods which represented 'organisation' and keeping on top of commitments. It suggests that for DWC, remaining highly organised is key to ensuring that work and care responsibilities run smoothly. Electronic devices, especially, support time-management, enabling DWC to synchronise schedules with co-caring partners, and allow DWC to perform work-related duties during designated periods of time between work and care roles. Technological aids and manual methods of organisation, therefore, play a vital part in DWC keeping ahead of a busy schedule. Coping strategies were not explored in the full IDEAL cohort, however, and the quantitative findings among the primary cohort of DWC (see Chapter 6.5) did not find an association of the use of positive coping strategies with better wellbeing. Therefore, while previous research with DWC has only explored the impact of preparedness for caregiving tasks on work-life conflict (i.e. Wang et al., 2013), these findings enhance knowledge about the problem-focused coping strategies DWC use to reduce family-to-work and work-to-family conflict and sustain work-life reconciliation.

8.6 Respite strategies

Many DWC interviewees referred to the need to take a break from both work and caregiving roles, to conserve energy by taking time out for themselves. To achieve respite from work and caregiving, over half of DWC (14 out of 24) utilised strategies which served to promote their own interests and protect their wellbeing. These activities consisted of mental and physical methods of relaxation and 'mindful' exercises (see Photo 8.3), which represent emotion-focused coping strategies. The respite strategies selected by DWC provided at least a minimum of a few minutes to a few hours of respite. In the following extract, one DWC described swimming and yoga as an escape from the emotional strains of work and care:

'*I have a full on, full time stressful job, and the sort of emotional stress I guess of thinking about supporting my dad, and so I, what I try to do is before and after work or at least one or the other, either go for a swim in the sea, which is my absolute joy and passion […] Or I practice yoga, or I just sit on my yoga mat and meditate or chill out […] I just love being in the water, of being supported by the water, of just thinking 'I don't care what else happens today, I've got in the sea' […]that's [yoga] more grounding […] both times, I haven't got my phone […] I'm uninterrupted, that's my time.'* (DWC16)

Photo 8.3 Yoga mat/Swimming costume as physical methods of relaxation and time alone (DWC16)

Other areas related to mental activities included a cognitive exercise App and listening to music (see Photo 8.4). In the following extract, the DWC similarly described how listening to a CD provided her respite from both work and care:

Researcher: *'And how does the object represent your experience as a working family carer?'*

DWC: *'Well balancing work and care and me time, cause there's three angles on it, and quite a lot of the downtime from the caring at the moment is devoted to the work. So I have to try and make sure that I get something that isn't that. So I guess […] this is the 'me' time.''* (DWC19)

Photo 8.4 CD as mental stimulation and *me* time (DWC19)

As with other DWC, this DWC was quite typical of the larger cohort of DWC. She was white, British, in her early sixties, and the primary carer for both parents with dementia, while balancing multiple part-time, low-income jobs. In this case, the DWC had a strict religious upbringing with clear cut rules installed about the roles of women and men, which meant that the DWC received little support from male siblings. Therefore, the absence of affirmation as the primary carer, motivated this DWC to listen to positive, reinforcing lyrics from a selected CD as a source of self-esteem.

An inspiring inscription on a key ring (see Photo 8.5) similarly served as mental and spiritual stimulation for one DWC, when work and care commitments became challenging:

'[…] obviously there are tools and techniques you know, like diaries and all that kind of thing, but actually for me, it's greater than that […] what care, caring has brought to my life, is an element of sort of spirituality […]. I don't follow a religion, but I do believe in something else greater than you know, me physically. You know like, because sometimes caring calls upon something that I have challenged myself to know that I even have, and so I kind of sometimes feel myself often sort of praying […] to 'please help me'. You know, 'give me the strength, give me something to do this, and balance all the other things you have to do in your life – work and all of those things, and socialise and try and have a bit of time for yourself.'' (DWC14)

Photo 8.5 Keyring inscription as *spiritual* motivation for balancing work and care (DWC14)

As a male, this DWC was more atypical of the DWC in primary and the larger cohort, who were predominantly female. This DWC was in his mid-forties and combining a working role with caring for his mother, who was in a care home.

Another DWC used a reading App (see Photo 8.6) to get absorbed in the stories of the book as a way of achieving respite between work and care:

'[…] I listen to audio books, just as a form of relaxation really, and I'm not very good at kind of meditating or like mindfulness in any other way. So I find that that's a really good escape, and it kind of distracts me from things, cause I get involved in the stories.' (DWC24)

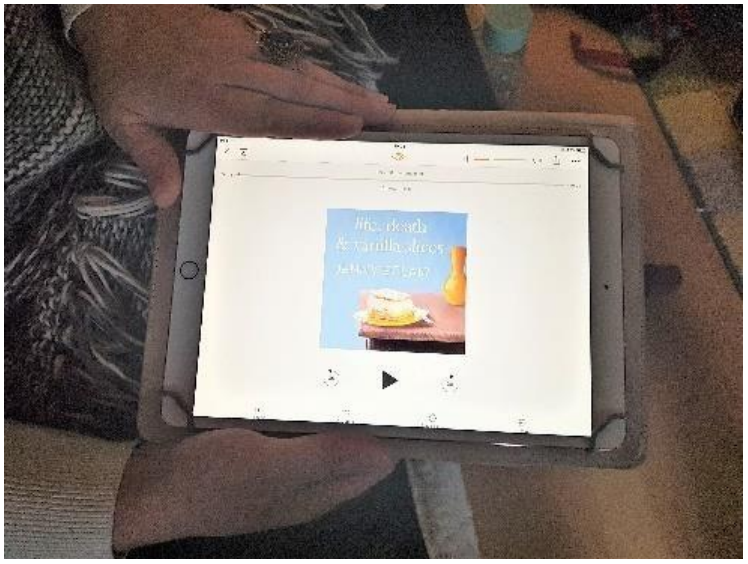


Photo 8.6 Reading App as an *escape* from work, care, and life responsibilities (DWC24)

One DWC used the physical activity of potato peeling as a distraction tactic for the PwD (see Photo 8.7), as this simple task served to release time for her to concentrate on other activities besides caregiving for short periods of time:

'Well a lot of my work is looking after foster children […] and in order to do that, we have to have regular mealtimes you know, and helping them with homework, and [we] have to have a very ordered life. At the same time, my mother with dementia is constantly wanting my attention […] wanting to feel useful not lazy […]. So I found that giving her a little job to do, peeling vegetables, actually frees me up to do the jobs that I need to do be doing […]. It takes her a long time, and so I am free then to get on with, with things I need to do.' (DWC21)

Photo 8.7 Potato peeler as a distracting task for the person with dementia (DWC21)

In another instance, a DWC spent his free time studying rocks and nodules (see Photo 8.8) as a way to fulfil a personal interest and to serve as an incentive for returning to study in the future:

'[…] So it's kind of like the hope of something in the future that […] you're working towards or a goal in life, something like this. But it's…right now it's not in my grasp to do it. (DWC20)

Photo 8.8 Rock/nodule as a way to fulfil a personal interest and long-term ambition (DWC20)

As a male primary carer, this DWC was atypical of DWC in the primary and larger cohort but was typical of the IDEAL sample in terms of age (i.e. mid-fifties) and ethnicity (i.e. white, British). This DWC was in the early stages of setting up his own business and was the primary carer for his mother with dementia. Focusing on a personal interest provided this DWC some semblance of autonomy outside of work and care, which enabled him to feel more positive about the future.

For other DWC (5 out of 24), the personal budget and additional funding provided a monetary incentive to achieve respite from caregiving and work responsibilities. Several DWC, for example, used the personal budget for activities such as a gym membership and brief vacations, as described by one DWC:

'That £300 grant is particularly encouraging to me. That they recognise that it's important to have some time out, and you can use it to go away on a holiday, or away for the weekend, but I feel to be able to join the gym for the whole year is really good, you know, and I really value getting out for that hour a week….' (DWC21)

This DWC was representative of the primary and the IDEAL cohort, being white, British, in her early sixties, and the primary carer of her mother with dementia. She particularly valued the respite offered by the personal budget. Unlike the majority of other DWC interviewed, her role as a foster carer and primary dementia carer meant that both roles often overlapped because they were performed in the household.

All DWC viewed the working role as a respite from caregiving, whilst only one DWC alluded to the caregiving role as a respite from work. In the following examples, DWC described employment as a 'break' from the stressors associated with caregiving and as an opportunity to socially integrate:

Researcher: '*And do you think having a job can help you as a carer?'*

DWC: '*Well it definitely gives me some time off to be hon[est]..It's ridiculous. What I've got (is) quite a full-on job, but I go to work to have a break really, sometimes.'* (DWC10)

'...sometimes it is a reminder I think if you can work that there is […] an outside world still.' (DWC14)

For one DWC, the benefits of work as respite, served to enhance his physical and social wellbeing:

'[…] most of the people in my team are into sports, running, athletics, gym, in one way or another […]. So there's that definite feeling of they all go, they all do something, so they're a very active team. So that sort gives you something to talk about and to engage into, which is you know, nothing really to do with the work. It's the people' (DWC2)

Another DWC highlighted the positive impact of going to work on his mental health (i.e. self-esteem):

'[…] I'm sure there is a certain, I dunno, a self-worth, self-esteemy sort of thing around working […]. So while perhaps working doesn't help [with] caring, I suppose it does help me in in the sense of...I don't know, doing something worthwhile, achieving goals, doing something […] I would be achieving something If I was a full-time carer, but it's not as obvious…' (DWC7)

8.6.1 Summary: Respite strategies

As discussed in the sustainability framework (see Chapter 3.3), DWC report using emotion-focused coping strategies such as mindfulness techniques, when there are no immediate challenges to attend to. These coping strategies emphasise the positive association of resilience with eudaimonic wellbeing, which refers to the experience of having a meaningful life and human flourishing via autonomous activities. Various respite strategies served to mentally and physically stimulate the personal interests of the DWC interviewees in the primary sample. As well as mental activities, some DWC who opted for physical strategies as respite still referred to the activity as a form of 'meditation'. This implies that DWC approached both mental and physical interests as a form of 'mindfulness', which boosted their resilience (Munoz et al., 2016) when handling the pressure of work and care responsibilities. These respite strategies enabled DWC to *escape* from the stressors associated with work and care. As highlighted in the

Theory of Human Need, autonomy of agency is a precondition which enables individuals to participate in their own form of life. For DWC, respite activities also provided a sense of autonomy from the identity of employee and caregiver, and these respite activities have been associated with improved QoL outcomes (Farina et al., 2017). Therefore, while previous research has found that participation in physical and social activities improves wellbeing for DNWC (de Oliveira & Hlebec, 2016), the findings reported in this thesis extendsuch benefits to the activities utilised for respite from work and care for DWC.

Having control over how the personal budget was spent, also provided some DWC the opportunity to achieve respite from work and caregiving tasks. As found by Jones et al. (2014), having control over a personal budget helps carers mentally and physically, by supporting a state of independence outside of the caring role. For the majority of DWC, however, the working role itself provided a welcome respite from caregiving duties, which has been reported also in previous research (Healthways & Coughlin, 2010). The findings reported in this thesis demonstrated that work also enhanced the wellbeing of DWC, where working status was associated with greater QoL (indicated by higher self-esteem and reduced relative stress) among DWC in the IDEAL cohort (see Chapter 5.3). In the quantitative analysis, however, emotion-focused coping strategies were not directly associated with better wellbeing outcomes among the primary cohort of DWC (see Chapter 6.5). Therefore, this qualitative component has revealed another contrasting finding from the quantitative research. This may reflect the way that the artifact elicitation technique more directly opens the personal voice of the DWC, and therefore encourages a more honest reflective response. In this way, the qualitative inquiry has enhanced knowledge about the emotion-focused methods DWC use to cope with the management of multiple roles.

8.7 Transferable skills between work and caregiving

For many DWC, skills which could be utilised between work and care, helped DWC to feel more positive about both roles. Over half of DWC (17 out of 24) highlighted that the transferable skills between work and care encouraged them to sustain the balance between roles. For the following DWC, the skills learnt in the working role were especially relevant to caregiving:

'[…] I think my work helps in being a carer. I think the other way [a]round, just because I work with people in distress all the time, so I'm used to dealing with that. I'm used to communicating with people whose perception of reality is very different.' (DWC24)

Other DWC (8 out of 24) described how combining work and care enhanced their empathic skills, as the following DWC highlighted:

'*[caring for my wife] improves my empathy in different situations, cause whereas before I was probably much more business-like. Now I think 'well okay, I can do this because this is what needs to be done from a business perspective, but what are the implications for other people it's gonna impact on?'* **(**DWC23)

Many DWC also perceived that combining roles have positive benefits for wellbeing in that they experienced better mental wellbeing, physical health, and overall alertness. In the following example, one DWC highlighted how combining work and care was mentally stimulating:

'...I would say I'm now juggling a lot more things, so that surely is helping me to maintain, to use my brain to remember and to plan to structure.' (DWC2)

Another DWC described the advantages of combining work with caregiving on their physical health:

'...it gets you out the house. I mean I've noticed I have a thing on my phone that tells me how many steps I do a day […] I did look at it the other day when I was at my dad's all day, and I'd done [laughs] 329 steps. So just the very act of going out to work, is improving my physical health [laughs] I should imagine, than being at my dad's house all day I would say.' (DWC4)

8.7.1 Summary: Transferable skills between work and caregiving

The transferability of skills between the workplace and the caregiving role enabled some DWC to manage both roles more effectively, and in some instances, improved empathic skills and overall wellbeing. For these DWC, then, work and care roles served to complement one another, and bettered performance in both. Other research (i.e. APPG, 2016) has similarly recognised that government and employers need to support greater recognition of the skills developed whilst carrying out caring responsibilities. As with other findings (Utz et al., 2011; Hoff et al., 2014), the transferability of skills demonstrates the importance of DWC having an identity as employees rather than just caregivers. In the quantitative analysis, comparisons between DWC and DNWC in the full IDEAL cohort demonstrated DWC reported greater self- efficacy (see Chapter 4.3), and higher self-esteem (in association with greater QoL - see Chapter 5.3) than did the DNWC, thus suggesting a potentially beneficial impact of employment for DWC. No previous research with dementia carers has explored in any detail the benefits of transferable skills for DWC. Therefore, the findings reported in this thesis add to the knowledge of sustainable work-life balance for DWC.

8.8 Support from home and work

Formal and informal sources of support are important for helping DWC sustain the balance between work, care, and personal life. In the sample interviewed here, formal and informal methods of support were considered necessary for all DWC, who used both formal i.e. professional respite carers (14 out of 24) and informal i.e. family/spouses (15 out of 24) caregiving support systems. The luxury provided by professional respite carers and family support alleviated stress and enabled DWC to go to work. Based on formal care support needs, one DWC selected an invoice to represent the professional caregiving support that she relied on to balance work and care (see Photo 9):

'[…] it is vital you know, to be able to feel that I can work, and know that she's being looked after, she's secure, and she's safe, and she's happy.' (DWC15)

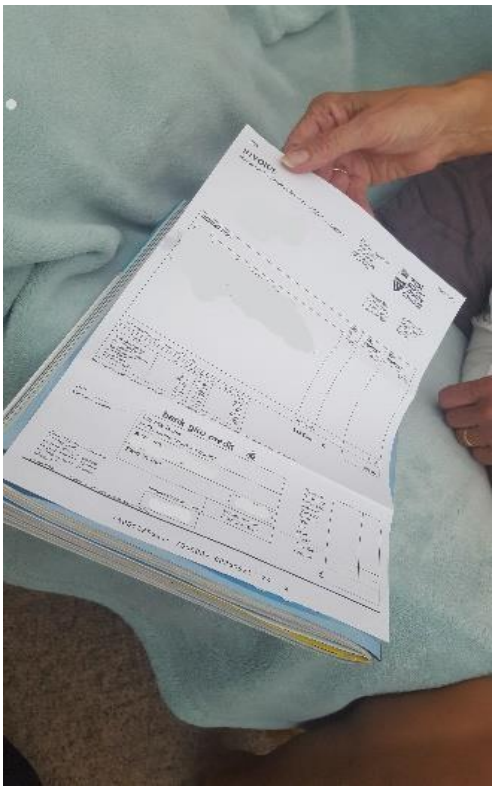


Photo 8.9 Care invoice as a way to fund respite care and remain in employment (DWC15)

Across interviews, many DWC stressed the importance of informal caregiving support from spouses and other family members for sustaining work-life reconciliation. Spousal support was imperative for one DWC, who was assisted in both work and care roles by her husband:

'My husband in particular. He's very helpful if I've got appointments I need to attend. He can stay with my mother, or similarly he can look after the foster children […] he's the main person.' (DWC21).

Some DWC selected artifacts that demonstrated the ability to keep in contact with formal and informal sources of support i.e. mobile phones (see Photo 8.10). The following DWC described how her mobile phone was essential for communicating with formal and informal support services:

'... it's my sister and I looking after my mum [correction] my dad. I spend so much time on the phone calling services, different services, carers, talking to my sister, texting my sister. Just had a long text from her just now. Yeah, the phone is vital to me, operating [laughs].' (DWC4)

Photo 8.10 Mobile phone as a source of *operating* with support structures (DWC4)

Informal emotional support from friends and family was also essential for several DWC (5 out of 24). In the following example, one DWC highlighted the positive examples set by friends who were in a similar position:

'*The examples that I see from our friends and the …I guess that the, the support that we give each other…is important to me, yeah, yeah, yeah.'* (DWC11)

Unlike the majority of DWC in the larger and primary cohorts, this DWC was male. Like most DWC in the larger and primary cohorts however, the DWC was white, British, and in his late sixties, retired and caring for his wife with dementia, while volunteering as a dementia support group leader. Friends of the DWC were also members of the dementia support group who provided mutual support. Voluntary hours also

enabled this DWC to prioritise requirements associated with the caregiving role, including care appointments and unforeseen caregiving crises.

Formal personal support structures (i.e. support groups, mindfulness course) were equally important to DWC and provided them with the knowledge to take better care of themselves. In the following extract, one DWC highlighted the usefulness of a support group that provided access to mindfulness training to achieve work-life balance:

'...I had an assessment from the Carer's Centre... I went on the mindfulness course through that which was free, which was really good.' (DWC6)

Informal workplace support was especially important to many DWC (13 out of 24). These DWC stressed the necessity of flexible working options, as well as supportive managers and colleagues. In the next example, one DWC discussed the importance of flexibility and emotional support in the workplace:

'My works policy is generally very good. So, they've allowed me to do both flexibly. Provided me with a laptop to work from home, provided whatever support they can there. There's an employee assistance programme where you can phone up for counselling. They do regular mental health at work days to make sure everyone's okay.' (DWC2)

In the following extract, the DWC stressed how the support of his manager and colleagues of his caring role, supported his ability to balance both work and care:

'*Well, to be fair work is very good […] by which I mean my colleagues, my Manager. My Manager especially […] a critical key thing is that my Manager is very understanding […] I can be very flexible with my work. I can work from home if needed, or I can, you know, if I needed to take an hour out […] I can work from home and do some extra hours in the evening […] first thing in the morning to make up for the time […] Equally my colleagues, you know, the team […]. They understand the situation…'* (DWC7)

8.8.1 Summary: Support from home and work

As highlighted in the sustainability framework (see Chapter 3.3), resilient DWC will seek out instrumental support to cope with the demands of work and care. Seeking instrumental support has also been described as a problem-focused coping strategy, which contributes to greater wellbeing. For all DWC in this study, work-life reconciliation was achieved by the emotional and instrumental support received at home and at work. Many DWC referred to both informal instrumental support (i.e. family and friends) and formal instrumental support (i.e. professional support). Such support systems can serve as a respite from the caregiving role but are also essential for enabling DWC to remain in employment (i.e. Yeandle & Bucker, 2017). Equally important for the primary sample interviewed here is the emotional support received from family, professionals, and support groups, which has a positive impact on wellbeing. Other research has demonstrated similar results (i.e. Pattanayak et al., 2011; de Oliveira & Hlebec, 2016), whereby larger social networks and seeking out support contributes to greater QoL and wellbeing. Furthermore, respite support has been linked to increased resilience among carers (Donnellan et al., 2014), and greater positivity towards the working role (i.e. Söderhamn et al., 2013). In the quantitative data from the IDEAL cohort, DWC were moderately satisfied with the level of support received from others in their social network (see Chapter 4.3). However, the quantitative analyses found no difference between DWC and DNWC in terms of social engagement and support received by friends. DWC were more satisfied with their personal relationships than were DNWC, which may be indicative that greater instrumental and emotional support from those closer to DWC was integral to their ability to combine work and care.

While instrumental and emotional support at home supported the work-life balance of DWC in the primary cohort, formal and informal support in the workplace was just as important to many DWC. At work, supportive managers and flexible schedules enabled DWC to fit caregiving responsibilities around work and helped them to feel valued. Previous research findings have suggested that flexibility in work schedules for carers can help to increase the likelihood of carers remaining in paid work (Hoff et al., 2014; Yeandle & Buckner, 2017), and is associated with fewer depressive symptoms (Wang et al., 2011). In some cases, DWC in the current sample managed to secure professional emotional support in their working roles, including counselling and mental health programs. Recent findings have also suggested that emotional and practical support

at work is linked to increased morale and reduced isolation among carers (SCIE, 2018). The use of emotional and instrumental support by DWC at home and work therefore, contributes to the limited understanding of the social resources employed by DWC to sustain work-life balance.

8.9 Bonded relationship between dementia working carers and people with dementia

The bond between DWC and PwD was another incentive for many DWC (16 out of 24) in their ability to sustain the work-life balance. One spousal DWC selected his wedding ring to represent the caregiving relationship (see Photo 8.11), and discussed how the relationship he has with his wife~~,~~ inspired him to combine work with care:

'[…] something that connects everything really I suppose, is my wedding ring, because that symbolises, you know, the bond with my wife, and it's an essential part of my life […] it's not the only reason I work, but one good reason I work is to you know, support our life together. So…I suppose it symbolises the life I've chosen to share with my wife…' (DWC7)

Photo 8.11 Wedding ring as a symbol of the carer-dyad relationship bond (DWC7)

For another DWC, the close relationship she had with her mother with dementia was represented by a novelty sign (see Photo 8.12), and symbolised the fun they had when they met up at the end of the working day:

'[…] I associate mum with friendship and fun […] Right, so my mum is my best friend and she's been my rock since I was born…and I associate my mum with fun and laughter, and good family times, so prosecco o' clock is the end of the working day, and I don't see my mum as someone who's ill at the moment. I see her as my mum.' (DWC18)

Photo 8.12 'Prosecco 'o clock' as a representation of *good family times* in the carer-dyad (DWC18)

As another DWC described, the advantages of a flexible working role, was having the time to build a closer relationship with the PwD:

'[…] I guess you know, caring sometimes can make me happy, and you know, there are moments where it does make me happy, and so the flexibility that it [work] brings, allows me to experience times with the person I care for, that I wouldn't have. I'd miss those opportunities […] it allows us to have a connection that we would have never had in the past. So there are very sweet happy moments being a carer has brought, and the job has allowed me to experience that I guess…' (DWC14)

This DWC was male, white, British, in his mid-forties, and caring for his mother with dementia, who was in a care home. The flexibility of working for different organisations as a manager and Adult Education Tutor, enabled this DWC to structure work around care commitments. The support provided by an understanding Manager and colleagues similarly strengthened his resilience to manage both roles.

8.9.1 Summary: Bonded relationship between dementia working carers and people with dementia

As discussed in the sustainability framework, resilience is mediated by the caregiving experience as well as psychological resources. Confirming reports from previous research, these findings demonstrate that the emotional bond in the carer-dyad relationship, is an important element of informal dementia care (Norton et al., 2009; Walters et al., 2010; LaFontaine & Oyebode, 2013; Rattinger et al., 2016). A close carer-dyad relationship also has positive gains for dementia carers (Tarlow et al., 200; Braun et al., 2010; O'Rourke et al., 2011; Cheng et al., 2013; Stiadle et al., 2013; Cheng et al., 2016; Hwang et al., 2017; Anderson & White, 2018). For many DWC interviewed, a positive caregiving relationship provided the motivation to continue caregiving whilst working. These findings were reflected somewhat in the caregiving experience between DWC and DNWC (see Chapter 4.4) in the full IDEAL cohort, where DWC feel less likely to have lost aspects of their personality due to caring (i.e. management of situation). This may indicate that employment supports the carer-dyad relationship, by providing DWC some respite from caregiving. Quantitative analyses also evidenced that reduced relative stress among DWC was associated with greater QoL (see Chapter 5.3). Not all elements of the caregiving experience were higher in DWC: caregiver coping scores were higher among DNWC (see Chapter 4.4). In the primary cohort, higher caregiving competence, low caregiving burden, and low role captivity, were associated with higher wellbeing (see Chapter 6.5). Comparisons between the IDEAL and primary cohort of DWC demonstrated that the primary cohort felt less likely to have lost aspects of their personality, but felt more role captivity, and lower caregiving competence (see Chapter 6.4). The differences in the caregiving experience between DWC in the IDEAL and primary cohort however, may be indicative of the greater caregiving needs of PwD in the primary cohort.

Overall, however, the significance of the caregiving relationship reported by the primary sample interviewees supports the quantitative analyses of the primary cohort of DWC and builds on the limited knowledge of DWC by highlighting the significance of the emotional connection in the carer-dyad relationship.

8.10 Discussion

Building on my quantitative analyses, this chapter set out to explore the strategies used by DWC to sustain work-life reconciliation. The emergent themes reinforce earlier findings regarding the strategies that support work-life reconciliation (i.e. support structures, respite strategies), but also contribute new insights which have not been explored in previous DWC research (i.e. coping strategies, transferable skills). Across interviews, DWC described support received with respite care from family and care professionals and formal carers. In quantitative analyses, the larger cohort of DWC also demonstrated more satisfaction with personal relationships than DNWC, suggesting that instrumental and/or emotional support from informal sources close to DWC may better support opportunities for DWC to remain in employment. During periods of strain, many DWC also employed assistance with emotional support from formal and informal sources at home and in the workplace. Instrumental methods of workplace support included flexible schedules that enabled DWC to work and accommodate both anticipated and unanticipated caregiving duties.

While no differences were found in strategies and wellbeing outcomes in quantitative analyses, interviews revealed that respite activities were an important emotion-focused strategy, and provided time out from both work and caregiving, by enabling DWC to focus on personal interests. For all DWC in this study, work itself provided a sense of respite from caregiving and enhanced overall wellbeing, as well as providing social inclusion. Although the value of respite care is not a new finding among carers and dementia carers, the qualitative findings highlight the importance of ‘me’ time among DWC.

One of the problem-focused strategies used to manoeuvre though daily challenges for DWC was to strategically organise the available time in the day to keep on top of tasks. Technological devices featured prominently in self-management strategies and were vital for remaining ‘in-sync’ with co-caring partners and performing manageable micro-tasks. The caregiving bond was another significant incentive for balancing work and care, with quantitative analyses similarly finding that a more positive caregiving experience contributes to better QoL and wellbeing.

The transferability of skills between work and care improved workplace performance for DWC, by enhancing patience and empathy with colleagues, clients or customers. The combination of both roles similarly served to improve several areas of

wellbeing for DWC, including improved memory and physical health. The quantitative findings also indicate that employment can serve to improve health outcomes for dementia carers, suggesting the value of reciprocal transferability of caregiving skills, and highlighting an area that needs to be recognised by employers.

Chapter 9:

Key findings, discussions, and conclusion: Synthesising stages 1, 2 & 3 and convergent parallel design

9.1. Introduction

The aim of this thesis was to extend current understanding of the factors which contribute to sustainable wellbeing among DWC. To achieve this aim, this thesis adopted a multidisciplinary mixed-methods design to holistically explore the challenges and strategies associated with sustainable wellbeing and work-life reconciliation among a larger national cohort and primary cohort of DWC. In Chapter 2, the overview of the research literature demonstrated that very few studies had been conducted with DWC, and that there is a considerable amount that is unknown about the impact of the combined roles of work and care on DWC. Most obvious was the absence of studies in the UK with DWC. This meant that knowledge about DWC was largely acquired cross-culturally. This was investigated using a mixed methodology of quantitative and qualitative data collection, that identified factors contributing to wellbeing, the conflicts to work-life reconciliation, and the emergent properties of sustainable work-life reconciliation among DWC. In Chapter 3.3, I described two theoretical frameworks that characterised the challenges of work-life reconciliation, and sustained work-life reconciliation for DWC, according to the background literature. In the first stage of this final chapter, I will review the thesis findings and how the thesis studies speak to current policy, and to the challenges and sustainability theoretical frameworks. I will then use the overall findings of sustainable work-life reconciliation to build a new working model of sustainability that synthesises the relationship between the quantitative and qualitative strands of the thesis. I will highlight the strengths and limitations of this thesis, and how the overall findings from this thesis guide directions for future research in this area. Finally, I will conclude with reflections of the personal challenges I encountered during this project, and how they were overcome.

9.2. Summary of findings

9.2.1 Challenges to sustaining work-life reconciliation for dementia working carers

Based on the fundamental principles behind the Ethics of Care (Chapter 3.3), the consequences of a lack of caring morality is that the care recipient is cared for to the exclusion of the self. In this thesis, several findings across the quantitative and qualitative analyses supported the indicators of the challenges theoretical framework. As described in the challenges framework, role-set theory recognises that various social arrangements can challenge the expectations of individuals included in various occupying roles, making conflicting demands difficult to manage.

For the DWC in this study, quantitative analyses demonstrated that multiple responsibilities are impacted by challenges associated with poor psychological resources associated with strain-based family-to-work conflict, and a negative caregiving experience (i.e. high caregiving burden; low caregiving competence; poor coping (in the caregiving role)). As reported by the primary cohort of DWC in semi-structured interviews, a poor caregiving experience is impacted by caregiving burden, which is reflected by statements that related to *isolation*, feeling *lonely*, and the *lack of choice* in being a working carer. This data reinforces and extends previous research findings reviewed in Chapters 1.2 and 2.6, that show that when the caregiving role is too intense, there is an increased risk of isolation and loneliness (i.e. Robison et al., 2009; Shah et al., 2010; Vitaliano et al., 2011; Zwaanswijk et al., 2013), and poorer psychological wellbeing (i.e. Alvira et al., 2015). In research with DWC (Wang et al., 2013), greater caregiving demands have also been associated with poorer psychological wellbeing for carers with high conflict between work and life. Therefore, the research findings explain further how the risks of combined work and care roles for DWC in this study are related to the increased likelihood of poor QoL and wellbeing, indicated by a poor caregiving experience and family-to-work conflict. This contributes much to the existing literature on what is understood about the impact of daily challenges to the QoL and wellbeing of DWC, whereby the implications of caregiving on the working role, especially, demonstrate the importance of exploring the bidirectional influences of work and life conflict for DWC.

As highlighted in the challenges framework, dysfunctional coping strategies are also characterised by poor psychological resources and a negative caregiving experience.

Among the primary cohort of DWC in this thesis, maladaptive coping strategies were related to poor self-management that included greater time-based family-to-work conflict and overlapping responsibilities between work and care due to role overload. In semi-structured interviews, several artifacts selected by DWC reflected the overlap between work and care roles. The conflicting demands between work and care meant that DWC had little time to fully commit to work and caregiving tasks, or to participate in respite activities which were based on personal interests, and/or social engagement. For many participating DWC, caregiving interfered with the working role, which meant that DWC were often distracted at work. This finding was explained by further quantitative analyses, whereby family-to-work strain-based conflict was associated with poorer everyday functioning (i.e. cognitive failures) among the primary cohort. As with previous research with dementia carers (Rosness et al., 2011), triple-duty caregiving responsibilities add to the feeling of exhaustion and further impact the available time DWC had to themselves. As highlighted in previous research (King et al., 2014), these findings imply that the interference of caregiving responsibilities with the working role, are stronger for DWC who experience more pressure from caregiving and time spent on caregiving tasks. The combination of work and care therefore, is a threat to overall wellbeing, as well as economic and professional wellbeing. Based on the previous literature which has explored coping strategies in terms of how DWC are prepared for caregiving tasks (i.e. Wang et al., 2013), these findings reveal more about the influence between work and care conflict and dysfunctional coping skills. In this thesis, time-management was a factor which suffered due to the impact of role overload from juggling multiple responsibilities, especially for DWC with young children.

The Care Act regarding individual control over care and support also fell short in several areas identified in semi-structured interviews. Firstly, the challenges of existing support systems included poor informal and formal support structures for PwD at home and work. At home, DWC were dissatisfied with the quality of support provided to PwD by social and healthcare professionals and formal carers, and the lack of support with respite care by close family members (i.e. siblings/-in law). For many DWC who receive formal respite care, the support provided by social services and health care services, was impractical and indifferent to the needs of some DWC. In many instances, DWC felt that care professionals and formal carers were insufficiently trained, and GPs and helplines were perceived as un-empathic. This led to concern among some DWC, that the

instrumental support required with basic caregiving duties by low-skilled care staff, impacted on their free time. Related to discontent with support for DWC was the conduct of carer reviews, which failed to identify the caregiving strains that DWC were under. Many DWC also pointed out issues associated with accessing information regarding specific care-related queries. At work, inflexible working schedules and unsupportive managers contributed to concerns among DWC about the absence of supportive structures for carers. Self-employed DWC, in contrast, highlighted a feeling of abandonment concerning any type of support in their employment. In some instances, DWC were unaware of workplace policies for carers, indicating that employers do not always highlight the rights of working carers to employees. As with previous research outlined in Chapter 2.6, the outstanding support needs of the DWC in this thesis were related to inadequate support structures. These findings suggest that in social care practice and in the workplace, the support highlighted in policy is not always translated into practice for DWC. Extending the limited information in existing literature, the dissatisfaction expressed by DWC with caregiving support structures provides valuable insight into specific areas of dementia support that interfere with work-life reconciliation. The risks to wellbeing of limited access to long-term support are related to a lower satisfaction with life (de Oliveira & Hlebec, 2016), and an imbalance between the needs of DWC with those of the PwD (Quinn et al., 2015; Hwang et al., 2017).

While the Care Act mentions support with participation in work and economic support, semi-structured interviews revealed that some DWC left thriving careers and generous salaries to seek careers that would accommodate caregiving duties. The financial constraints of caregiving restrictions limited choices and autonomy for some DWC and added to the burden of care. The threats to socioeconomic status for DWC were associated with the restrictions of care allowance (CA), based on regulations associated with income threshold and low CA generally. As research has highlighted that CA only supports carers who are in low paid or part-time work (Fry et al., 2011; Glendinning et al., 2015), DWC felt restricted by their inability to work more hours whilst claiming CA. Policies associated with income caps therefore, mean that DWC do not earn much more by working and receiving CA than do full-time carers. Further frustrations were directed at the inflexibility of the personal budget in relation to the inability to use funds towards the daily costs of care. Some DWC also experienced the emotional and financial strain associated with selling off assets belonging to the PwD to cover care home fees, and the uncertainty of their own pension security in later years. Many concerns regarding work-

life reconciliation among DWC, therefore, were related to financial pressures. For many DWC, the lack of financial support is evidence of under-appreciation by the government for their caregiving efforts. The findings of this thesis extend knowledge about the socioeconomic profile of DWC and enhance existing DWC literature that has not explored the economic factors associated with the conflict between work and care.

To improve work-life reconciliation, many DWC discussed formal methods of respite care for PwD, in terms of care service support. Respite care with the physical needs of PwD was an important resource which many DWC felt was in short supply. DWC described that additional support, with the relief of some personal care duties, would provide them with more quality time with the PwD, and reduce the strain associated with work, care, and life conflict. At the same time, DWC suggested that care professionals and formal carers and DWC themselves need to receive better training, to enable DWC to feel more confident in performing caregiving duties and utilising professional services. Other DWC referred to the need for more input from family members, with limited support from siblings/in-law being common across DWC. Based on the support services employed by DWC to sustain mental/emotional wellbeing, some DWC suggested that access to dementia support groups and counselling, would be beneficial for maintaining emotional health. Moreover, while dementia awareness strategies have been implemented across the UK, many DWC still felt that there needed to be more public awareness about the issues surrounding a dementia diagnosis, to reduce ignorance about the disease.

In the workplace, DWC explained that support structures could be improved by ensuring that the working environment has transparent strategies in place to support flexible work schedules and greater recognition of the caregiving role. To ease the financial burden associated with limited work hours, DWC suggested that tax breaks and more sustainable caregiving allowance would go some way to compensate for lost revenue from limited working hours and/or career demotion. Allowing DWC more choice in how they spend their personal budget can also personalise support for DWC and empower DWC to feel well supported in their rights as a working carer. In the longer term, learning from other countries might be helpful for a more conceivable solution to the financial crises of care costs in the UK, and the expanding elderly population.

Therefore, while the recommendations of DWC generated a fresh perspective on how work-life reconciliation can be improved for DWC, the dissatisfaction with existing support structures warns that greater efforts need to be made towards the implementation of policies, if DWC are to remain in employment.

In summary, the overall findings associated from the quantitative and qualitative strands add considerably to what is already known about the factors contributing to work-life balance and reconciliation for DWC. In the following section, I synthesise the quantitative and qualitative findings based on the theoretical sustainability framework, to develop a new working model of sustainability for DWC.

9.2.2 Sustaining work-life reconciliation for dementia working carers

As highlighted by the Theory of Human Need, the fundamental needs of individuals are that they can achieve autonomy in their day-to-day lives. The Ethics of Care similarly highlights that an ideal model of moral maturity accounts for the needs of both carer and the cared for. For individuals with multiple responsibilities, role balance is achieved when individuals have the capacity to engage in their roles with equal devotion, attention and care. The sustainability framework characterises resilience for DWC as mediated by positive psychological resources and a good caregiving experience. With these resources in place, DWC are more likely to utilise positive coping strategies, including problem- focused coping skills (i.e. problem-solving, time-management, and seeking social support), and positive emotion-focused coping strategies (i.e. mindfulness/meditation).

In the quantitative strand of this thesis, the larger cohort of DWC in the IDEAL Study reported greater psychological resources (i.e. higher self-efficacy and self-esteem) and a better caregiving experience (i.e. reduced relative stress and greater situational management) than DNWC, with both higher self-esteem and reduced relative stress being associated with a better QoL. Between group comparisons for the full and primary cohort of DWC, however, showed that group differences were apparent on most measures associated with caregiving experience. In the primary sample, DWC had poorer wellbeing overall, which was indicated by higher scores in role captivity, and lower scores of caregiving competence. On the other hand, DWC in the primary cohort were more confident than the full cohort of DWC in managing the caregiving role. In this case, reduced wellbeing among the primary cohort of DWC was proposed to reflect caring for individuals with greater dependence needs, which has been associated with lower QoL and wellbeing in earlier studies (Nurfatihah et al., 2013; Wang et al., 2013; Cheng, 2017). Within the primary cohort however, lower caregiving burden, less role captivity, and a greater sense of caregiving competence was associated with better wellbeing outcomes,

as well as lower time-based and strain-based family-to-work conflict. As discussed in Chapter 2.6, positive factors associated with the caregiving experience (i.e. positive aspects of caring and feelings of accomplishment) are related to how dementia carers sustain caregiving (Hwang et al., 2017). DWC, compared to DNWC, in the larger cohort are also more satisfied with their personal relationships. While previous research with DWC has not explored the impact of social relationships between DWC and DNWC, other carer research suggests that employment increases the likelihood for greater social integration and partaking in activities of interest (Utz et al., 2011). The benefits of employment for DWC in this thesis, then, may have contributed to improved psychological resources, a better caregiving experience, and greater satisfaction with personal relationships. Therefore, while previous research with DWC has contributed to furthering knowledge about the negative impact of combining work and care on the QoL and wellbeing of DWC, the thesis findings generate more understanding of the resources which assist sustainable wellbeing for DWC.

Causal factors associated with higher QoL among DWC were not explored in the quantitative analyses, but the findings did suggest that employment might serve as a respite from the responsibilities of care and protect against the detrimental effects of caregiving stress. In line with previous research, the quantitative analyses showed that males experience greater QoL and wellbeing than females, with younger age being another factor for better QoL. Gender differences in family-to-work conflict have been attributed to the fact that women are more likely to assume prime responsibility for managing home-related crises (Wood & Eagly, 2002). In terms of QoL, then, the demographic differences obtained between DWC and DNWC demonstrated a potential vulnerability among older female DWC.

In the qualitative strand of the thesis, semi-structured interviews revealed that DWC employed many creative methods to manage work and care responsibilities, which protected and enhance their overall wellbeing and were reflected in the artifacts chosen to represent work-life balance. The resources utilised to achieve work-life sustainability were related to positive coping strategies. As highlighted by the conceptual framework for sustainability, the Transactional Model of Stress and Coping, problem-focused coping strategies include active coping strategies, such as problem-solving, time-management, and obtaining instrumental social support, while emotion-focused coping strategies are also associated strategies such as prayer, mindfulness, and meditation. The first of the emergent themes discussed was related to time-management (i.e. organisational skills) for

DWC. The importance of synchronised schedules with co-caring partners (i.e. spouses and adult children) were emphasised by DWC, as well as utilising down time between work and care to perform work-related micro-tasks. Many DWC describe the reliance on modern technology (i.e. iPads, smart phones) and manual strategies (i.e. diaries, post-it notes, whiteboards) to manage the many responsibilities associated with work and caregiving and to keep on top of a busy schedule. As found in previous research with dementia carers, physical and emotional strain is reduced by overcoming obstacles, managing conflicts and long-term planning (Alves et al., 2017). Moreover, positive coping strategies (i.e. cognitive reappraisal, time-management) are correlated with reduced burden, lower rates of depression (Papastavrou et al., 2011), and a greater psychological QoL (Hwang et al., 2017).

Developing previous research that explored one-way coping strategies among DWC (e.g. Wang et al., 2013), these findings provide a more detailed account of the specific problem-focused strategies used by DWC to manage daily challenges, related to the bidirectional impact of work, care, and life conflicts.

Contingencies that enable DWC to achieve respite through activities of personal interest contribute towards protecting DWC from role overload. For DWC in this thesis, respite activities were structured into designated slots of time between work and care responsibilities. To achieve respite from work and caregiving, many DWC utilised both mental and physical activities, which served as 'mindful' relaxation. Such strategies enabled DWC to partake in personal interests which served to retain their autonomy. For some DWC, the personal budget served as an incentive to invest in respite activities. As research has shown, dementia carers with an active participation in physical and social activities have a higher satisfaction with life (de Oliveira & Hlebec, 2016). For the majority of DWC, however, the working role itself provided a welcome respite from providing care and played a potential role in protecting DWC from caregiving burden, a finding also identified by previous research (Healthways & Coughlin, 2010). Therefore, while some evidence has shown that the wellbeing of dementia carers is benefitted by respite activities, these findings generate more insight into the actual strategies used to achieve respite between work and care for DWC.

The use of social support as a coping mechanism is also positively correlated with physical and psychological QoL domains (Pattanayak et al., 2011). Another method DWC adopted to achieve sustainability, was the utilisation of instrumental and emotional support at home and work. At home, DWC opted for the services of formal caregivers and/or

family members to take over caregiving duties during working hours. The instrumental support received from family and care services served as a respite from the caregiving role but was also essential for enabling DWC to remain in employment. Previous work (i.e. Söderhamn et al., 2013) has also confirmed that when respite support is in place, DWC feel more positive about the working role.

Equally important was the emotional support received from family/friends, support services, and support groups, which had a positive impact on wellbeing. Where carers did not have access to the informal emotional support identified, formal emotional support served to provide some relief for emotional strain. The use of emotional support with care to sustain psychological health therefore, was common among many DWC who felt the burden of being the primary carer. At work, DWC sought instrumental support such as access to flexible working hours and working from home. Previous research with DWC (Wang et al., 2011) confirms that workplace flexibility at least, is associated with fewer depressive symptoms. Emotional support was also utilised at work and was related to approachable and supportive managers and colleagues, where previous research has found that a trusting, professional relationship with line managers is essential for carers generally (Hoff et al. 2014). In some cases, emotional support in the workplace was available through mental health awareness programs. Based on the limited work on the support structures utilised by DWC, these findings highlight the specific areas of instrumental caregiving support and emotional support sought by DWC. Understanding the systems that support the work-life balance provides more knowledge about the structures that aid work-life sustainability at home and in the workplace for DWC.

Another novel finding from semi-structured interviews that contributed to the DWC caregiving literature, is the significance of the skills that can be transferred between work and caregiving roles. The ability to utilise skills learnt in the workplace in caregiving and vice versa enabled some DWC to manage both roles more effectively, and in some instances, improved their empathy and overall perceptions of life. These skills were especially important in installing the confidence in DWC to balance work and care, and supported DWC mental and physical wellbeing. Moreover, the sheer act of balancing both roles competently enabled some DWC to feel ‘active’ and ‘alert’. This in turn, had a positive impact on overall wellbeing, confirming previous research findings (Phillips, 1995; Gignac et al., 1996; Kimura et al., 2015; Carers UK, 2017). As with previous research (Utz et al., 2011), DWC also emphasised the importance of continuing to have an identity as employees rather than just caregivers (Hoff et al., 2014). These findings

contribute new insights to the areas of sustainability for DWC, which have not been explored in previous research. The skills that are learnt in the caregiving role can enable DWC to feel appreciated at work, indicating how caregiving skills should be recognised more by employers as skills which are transferable to the workplace.

As other research has recognised, a close carer-dyad relationship has been associated with many positive gains for DNWC (Tarlow et al., 2004; Braun et al., 2010; O'Rourke et al., 2011; Stiadle et al., 2013; Cheng et al., 2016; Hwang et al., 2017; Anderson & White, 2018). Another contribution of this thesis to the limited knowledge of DWC was the significance of the emotional connection between carer and care-recipient. For many DWC, the bond in the caregiving relationship was one motivating factor which incentivised them to sustain the balance between work and care roles.

9.3. A new model of sustainable wellbeing and work-life reconciliation for dementia working carers

The areas of sustainability found across the quantitative and qualitative findings, provided evidence for a new working model of sustainability for DWC (see Figure 9.1). The psychological resources associated with sustainability for DWC were related to: high self-esteem; high self-efficacy; low strain-based family-to-work conflict. A more positive caregiving experience was associated with: low caregiving burden; low relative stress; low role captivity; high caregiving competence; bonded relationship between PwD and DWC. Social resources were associated with a high satisfaction with social relationships. Included in this model is a new factor - 'cognitive resources' which describes bi-transferable work and care skills. Strategies common to problem-focused (i.e. time-management, instrumental support) and emotion-focused coping (i.e. emotional support, respite strategies) were essential for most DWC to achieve a balance between roles. The strategies that have proven effective for DWC work-life reconciliation, therefore, can be translated to policies that protect DWC wellbeing, in practice.

Figure 9.1: Working model of sustainable wellbeing and work-life reconciliation for dementia working carers

Self-assessed psychological and personal resources					
Psychological, cognitive, and social resources, and caregiving experience				**Coping strategies**	
Psychological resources	**Cognitive resources**	**Social resources**	**Caregiving experience**	**Problem-focused coping**	**Emotion-focused coping**
High: self-esteem; self-efficacy	Transferable skills (utilising work-to-family/family-to-work skill set)	High: satisfaction with personal relationships	High: Caregiving competence	Informal instrumental support: Family/friends spouses - respite care; Workplace – flexibility	Informal emotional support: Family, friends, spouses; Dementia support groups, counselling, mindfulness training
Low: strain-based family-to-work conflict	Low: Cognitive failures		Bonded relationship between PwD and DWC	Formal instrumental support: Professional care	Formal emotional workplace support**:** Mental health awareness programmes; Supportive Managers/Colleagues
			Low: caregiving burden; relative stress; role-captivity	Time management: Organisational skills; Low time-based family-to-work conflict	Respite strategies: Physical and mental activities – linked to personal budgets; employment

Sustainable wellbeing and work-life reconciliation for dementia working carers

9.4 Strengths, limitations, and future directions

9.4.1 Strengths

The findings described in this thesis demonstrate the complex interrelationship of the psychological resources, caregiving experience, care-recipient dependency needs, and the mutuality of work and life interference, on QoL and wellbeing outcomes for DWC. The work contributes new insights that have not been explored in previous DWC research (i.e. outstanding support needs, respite strategies, transferable skills). Furthermore, the bidirectional impact of work-to-life conflict has not previously been explored in the literature on working carers. This was a limitation in the literature, since previous research has found that the effort involved in maintaining both roles can reduce the performance in both and impair the overall wellbeing of carers.

This thesis also contributed more to understanding the coping strategies of DWC to achieve sustainable wellbeing, and the impact of existing support structures. The overall findings from the quantitative element of this thesis demonstrated the importance of family-to-work interference on work-life reconciliation, and specific psychological (i.e. self-esteem and self-efficacy) and social resources (i.e. satisfaction with personal relationships). Furthermore, more intricate aspects of caregiving burden were revealed in quantitative analyses (i.e. caregiving competence, role captivity, caregiving burden, management of situation). The overall findings from the qualitative strand of this thesis also contribute new insights to the challenges facing DWC, which have not been explored in previous DWC research (i.e. the bidirectional impact of work and life, and the outstanding needs of PwD and DWC), and the strategies used by DWC to sustain work-life balance (i.e. organisational skills, transferable skills between work and care, and the caregiving bond).

Another strength of this project was the considerably large sample of DWC from the national IDEAL Study database. In addition to the advantages of more in-depth analyses of working status, this large dataset provided a broader set of measures, which revealed more about the role of psychological factors, carer experience and social influences among DWC. Likewise, the mixed-methods study design was the first performed with DWC and enabled different methods of data to be clustered and compared to generate a broader collection of data, whereby qualitative analyses enriched the quantitative findings by emphasising aspects of unsustainable and sustainable

wellbeing such as physical health, cognition, and social support. This meant that the methods selected to explore the challenges of sustainable wellbeing and work-life reconciliation, and the strategies which support wellbeing and sustainable work-life reconciliation among DWC provided a more robust knowledge base about those factors which can be translated to larger groups of DWC.

One unique contribution of this thesis to the existing literature on DWC was the inclusion of artifact guided semi-structured interviews. Including an object of personal significance allowed DWC to comfortably and creatively reflect on the various coping strategies they employ to achieve work-life reconciliation. This meant that, in most cases, DWC were more open to discussing their experiences, while retaining 'control' during the interview process. Moreover, these artifacts provided a deeper insight into DWC experiences than might normally be obtained during 'typical' interviews, by providing a visual and deeply personal snapshot of the challenges facing DWC, and the strategies they felt provided them the best support for sustaining wellbeing and work-life reconciliation. As little is understood about the strategies DWC employ to sustain work- life reconciliation generally, the rich collection of data for this thesis served as a uniquely detailed resource through which to enhance knowledge regarding the wellbeing of DWC.

9.4.2 Limitations

This study also has limitations which resulted from the dependencies of IDEAL data and empirical research resources. First, the study design for the primary cohort of DWC was developed before the data from the IDEAL Study was available. This was due to unanticipated delays in data preparation and release (resulting from a major move of the study team from Bangor to Exeter University). As a result, research instruments selected for the primary cohort study were chosen without knowing the factors that contribute to sustainable wellbeing among the national cohort of DWC. This meant that prominent research findings based on the differences between DWC and DNWC (i.e. QoL, self-efficacy) were unexplored in the primary cohort. Decisions in the early stages of the research process, however, were based on areas referenced in the background

literature, and on considerations of ease of administration within a restricted time period. At the same time, it was the case that this research originally set out to explore the wellbeing of DWC, in line with the emphasis on maintaining carer wellbeing highlighted in the Care Act, and QoL was not a primary target variable. Therefore, while the quantitative element of this thesis captured a difference among the IDEAL cohort of DWC and DNWC in QoL and not wellbeing, the thesis findings nevertheless indicated a revealing relationship between wellbeing and indicators of social support especially, which makes an original contribution to existing literature. QoL is an area to be addressed in future related projects with DWC.

Second, the selection of measures extracted for quantitative analyses were based on those available in the IDEAL dataset. Therefore, any other factors that could impact QoL and wellbeing may not have been captured. For instance, as the carers in this study supported persons with different dementia diagnoses, further variations in QoL and wellbeing outcomes may have emerged if the diagnostic differences between groups were explored. Moreover, the cross-sectional nature of quantitative studies meant that causations between variables could not be established.

As is typical in other studies with dementia carers, most participants in both the larger and primary cohort of this study, were white and British. In the primary sample, DWC were also from the southeast of England, where living costs are typically higher in comparison to some other areas of the UK (ONS, 2017). This means that the experiences of DWC in this thesis may not necessarily reflect the experiences of other DWC across the UK. For instance, in this study, only one DWC was of minority background, which reflects the predominant culture of white, British people in this region. Other studies have similarly described the recruitment of ethnic minorities as a problem in research generally (Morrison et al., 2016). As highlighted by Morrison and colleagues, recruiting ethnic minority groups can also be an issue if the researcher's ethnicity is white, British, or if the population is under-representative of ethnic minorities in the targeted areas.

Finally, one main demographic difference highlighted between DWC in the full and primary cohort was in educational attainment, with the primary sample of DWC being more likely than the IDEAL sample to have degree and postgraduate experience. In other research (Walker & Yu Zhu, 2013) higher education is arguably likely to lead to a more sustainable work-life balance, based on greater earning capacity among graduates. However, in this thesis, pressure appeared to be greater among the primary sample of DWC, with greater overall caregiving burden, potentially associated with the greater

dependency needs of PwD in the primary sample. The implications of these differences are that DWC in the primary sample may be less representative of the more 'typical' population of DWC who care for PwD with lower dependency needs. Moreover, while the overall similarities between DWC in the full and primary cohort were based on the majority of DWC in both cohorts being around their mid-fifties on average, and predominantly female spousal carers, these findings may translate less well to DWC who fall outside of these demographic profiles.

9.4.3 Future directions

This was the first in-depth study of its kind with DWC. Based on the working model of sustainable wellbeing and work-life reconciliation for DWC, further work should explore the factors which contribute to sustainability found in this research, with other groups of DWC to test the validity and reliability of these findings in other samples. Future research should follow up the response of carer policies based on the new working model (see Chapter 9.3) of sustainability for DWC and the recommendations to current policies. The results of these studies would provide valuable data relevant to whether proposed changes are being enforced, and how they are received by DWC. Further work between DWC and DNWC should generate more data based on areas which were not explored in this study but are still important to wellbeing (i.e. satisfaction with life). Exploring other indices of wellbeing would indicate whether working status has other advantages to the overall wellbeing of DWC. The between group differences found in QoL and wellbeing outcomes for DWC and DNWC also warrant further investigation of the relationship between QoL and wellbeing for DWC, based on differing underlying constructs. In this study, the health indicators of QoL were compared between DWC and DNWC, as opposed to other broader indicators of QoL (i.e. personal beliefs, relationship with the environment – WHO, 2018). Analysing causation between variables would similarly provide more descriptive detail on the risk factors and mediators of QoL and wellbeing outcomes. The few studies conducted with DWC also suggests that work-to-life and life-to-work indicators of conflict should remain. Further, positive aspects of caregiving would be better balanced out by utilising complementary measures of job satisfaction, when considering the beneficial aspects of dual roles.

Future work in this area should also explore the contributions of demographics to sustainable outcomes for DWC. As the larger cohort of DWC were caring for PwD with variable dementia diagnoses, other studies should consider controlling for specific

diagnoses based on behavioural differences in diagnostic criteria. Further explorations would also benefit from seeking out DWC from different ethnic groups to assess whether there are variations in caregiving experiences within the UK, dependent on religious beliefs, and cultural identity. At the same time, addressing how the experience of DWC in this study translates to DWC from other parts of the UK would provide a valuable contribution to the literature in terms of how DWC sustain work-life reconciliation from less affluent backgrounds.

Finally, while exploring gender differences was not an objective for this thesis, quantitative analyses confirmed that irrespective of working status, males and younger DWC experienced better QoL and wellbeing. These findings are important and demonstrate that potentially very little has changed in terms of females managing the bulk of caregiving tasks. Therefore, while female gender and older age appear to be risk factors, further analyses should also consider the barriers between age and gender, as a potential threat to work-life reconciliation.

9.5 Summary

This thesis has demonstrated that DWC have many strategies for sustaining the work-life balance. The results from this thesis also suggest that major improvements in social care, workplace policies, and further research are all necessary to maximise the sustainability of work and care responsibilities for DWC. Supporting DWC to live well while caring for a relative with dementia reduces the risk of employers prematurely losing skilled employees, where evidence suggests that providing weekly care for just 10 or more hours, increases the chances that carers will permanently leave the workforce (King et al., 2014). Therefore, while the age and number of working carers and instance of dementia is projected to increase over the coming decades, it is also imperative that further work is funded with DWC from various backgrounds. Financing future research with DWC would ensure the validity and reliability of these findings is transferrable to DWC with different profiles from the DWC in the larger and primary cohort of this thesis, which were predominantly female and middle-aged DWC of care-recipients with Alzheimer's. Furthermore, exploring the causal relationships between those factors that contribute to sustained wellbeing and work-life reconciliation, would provide a greater understanding of how self-assessed psychological and personal resources are utilised by DWC.

The new working model of sustainability and the recommendations for policy are proposed as early-stage benchmarks for improving and sustaining the wellbeing of DWC in the short term and the foreseeable future. Acting on the recommendations provided by DWC in this thesis would enhance personalisation in care and empower DWC to make choices with less risk to their wellbeing and economic independence. Finally, improvements to the working environment would support the longer-term employability of DWC, where organisations risk losing the skills of employees whose personal responsibilities are not catered for by the workplace.

9.6 Final reflections

While highlighting the contributions of this thesis to the caregiving literature are important, it is also necessary to outline the more personal challenges that I, as the author, have experienced during this research process, and how I overcame these challenges, in order to strengthen my academic skills and personal development.

The first challenge I faced was relayed in my reflective statement (Chapter 3.2) in which I described my limited knowledge about dementia carers. Knowing very little about the challenges facing DWC was also related to the limited availability of DWC studies in the research literature. Furthermore, my limited knowledge about the sociological studies of carers in general meant that my theoretical understanding was biased, being embedded mainly in the psychological theories of care. This meant that the validity of research which was centred in social care was threatened by my experience as a monodisciplinary researcher. However, this also provided an exciting opportunity for me to learn more about the theories behind caring and the existing data on dementia carers, to introduce a substantial contribution to this knowledge gap in the caregiving field. When exploring the literature, one of the obstacles I faced was the integration of sociological and psychological disciplines. As highlighted in Chapter 3.2, my main background is predominantly psychology-centred, and therefore, I knew very little about what sociology databases to explore for literature, the policies applicable to working carers, and the presentation style expected in sociological disciplines. Furthermore, my experience in the more ‘creative’ elements of qualitative methods (i.e. incorporating objects into semi-structured interviews), was also limited, as was the more complex modes of quantitative analyses (i.e. multiple regressions) in my psychological experience. This was certainly a huge undertaking, which was both daunting and liberating.

Moreover, this required me to fuse together those elements of sociology which are focused more on the qualitative aspect of analyses, and psychology as a more objective mode of interrogation.

As a solo-researcher, this was particularly intimidating in the early stages of the research process. Unlike a taught degree, the solo researcher is required to seek out the knowledge relating to their own research, and to trust in their own competency. With a background predominantly in psychology and mental health, I began the PhD feeling a little out of my depth and a little 'rusty' to say the least. To minimise the adjustment between disciplines and to reduce the isolation of conducting a PhD, I utilised the experience of my supervisors, and immersed myself into the Sociological elements of study by completing the ESRC-funded PGDip (Postgraduate Diploma) in Social Research Methods at the University of Sussex. I selected research modules on the basis that they could be applied to the content of this thesis (i.e. quantitative and qualitative analyses, social inclusion, policy and practice). Also, relevant to the more aesthetic concerns of the thesis presentation were the internal courses that I attended at the University of Sussex. This included guidance based on layout and searching databases for relevant articles and other PhD theses. Not only did these courses encourage me to seek out much of the epistemological knowledge that I was lacking due to my background, but they also provided a productive way to socially integrate and discuss the challenges I was facing in my research. At the same time, completing essays and receiving feedback strengthened my academic aptitude and improved my self-confidence, which enabled me to reconnect with my own potential. Likewise, the challenges of being a solo researcher were also offset by having the freedom to trust my own ingenuity and seek solutions independently, which enabled me to further develop my research skills.

During this time, I also faced the challenge of ensuring that all ethical considerations and precautions were in place to protect participants when creating the study design. This was particularly difficult due to the stringent methodological IRAS (Integrated Research Application System) application process, which meant that all possible preventions to foreseeable and unforeseeable harm to DWC were accounted for. Understandably, the strict procedure associated with IRAS ethical reviews, means that some delay to study approval is anticipated. For this thesis, this meant that recruitment occurred some fourteen months following commencement of the PhD – at least five months later than anticipated. As with all other responsibilities associated with conducting a PhD, shifting deadlines are especially stressful and can result in

considerable setbacks to a project. However, this experience also encouraged me to continuously review my timelines, introducing an element of flexibility and adaptability into my research plan, while seeking the support of supervisors and colleagues to ensure that any deferment in ethics approval, would not impact the recruitment of research participants.

As highlighted in my reflective statement another one of my concerns when beginning this project~~,~~ was my limited 'real world' experience with dementia carers. This made me question whether I, as a novice researcher, could fairly conduct an interview with dementia carers, remain empathic to their difficulties, and relate to the more difficult elements of being a working carer who supports an individual with complex needs. However, while conducting interviews, I found that the process of relating to DWC and aligning with their experiences of emotional upheaval and work-life conflicts came naturally, based on my own circumstances as the sole support for my parents, while conducting my studies at a distance. In this sense, I could concur with the challenges associated with DWC descriptions of work and life conflict, whereby the aspect of personal expectations from family impinge on the responsibilities associated with the professional role, which can impact on wellbeing.

Another aspect of the thesis which I found particularly challenging and unanticipated in the early stages, was readjusting to an intense academic routine after several years away from it. In this sense, I felt I had to 're-learn' many of the techniques for searching databases, as well as building on my previous knowledge to 'update' my skills. The further challenge associated with spending several years away from academia is the increased likelihood of 'imposter syndrome', or feeling 'not good enough', which I fell victim to on several occasions. This self-doubt, coupled with the daunting prospect of the organisational requirements and time-pressures of a project-linked studentship, was quite overwhelming as a newcomer in a complex role. Conducting a project-linked, interdisciplinary studentship for instance, meant that multiple bodies required progress updates, which placed many demands and pressures on the completion of the PhD, which was a potential threat to my own work-life balance. The teams involved in the completion of the project included both supervisors, internal contacts within the University of Sussex (i.e. Research Governance, recruitment teams), research co-ordinators in the IDEAL team, the project funders, and external contacts (i.e. study participants)). At the same time, however, I found that having to meet deadlines and organise my time effectively around multiple commitments meant that much like the participants in my study, I developed

better time-management strategies which enabled me to find a balance between the many commitments of the PhD, while still reserving time for myself. During this time, through the support of colleagues and internal courses, I also found better ways to take care of my own wellbeing (i.e. adequate nutrition, mental health support) to ensure I had the energy to commit to this role effectively and to see it through to completion.

As a final note, while I have highlighted the many challenges associated with conducting a PhD, the benefits of this experience have far outweighed the obstacles I have confronted on this adventure. I have gained a tremendous amount of experience in both sociological and psychological elements of research skills and theoretical knowledge and have broadened my qualitative and quantitative skills of data collection and analyses. During my own personal journey, and through the experiences of my participants, Ihave likewise learnt strategies to manage the challenges in my personal and professional life and have come to value the importance of nurturing my own wellbeing. Before I began this project, my ability to balance the multiple responsibilities in my own life was haphazard, being limited to my own conjectures about the meaning of work-life balance. Based on my interactions with my participants and my own experience as a source of support for my parents, I have inevitably been impacted by the negative and positive experiences that affect DWC daily. While I can relate on some level to the distress described by DWC, I have also been inspired by their positive outlook during times of stress, and the methods DWC use to reduce the impact of strain. Therefore, I am grateful that the professional and practical experience I have garnered during this PhD, and the lessons provided by colleagues and participants, have taught me not just the strategies which support a better work-life balance, but also have enabled me to value the importance of work-life balance in my future endeavours.

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Appendix I:

List of research development training, research seminars, conferences, and journal publication

Researcher development training

The University of Oxford. *Mixing it up: understanding and using mixed methods research in social sciences.* (14 October – 2 December 2015).
University of Surrey (ESRC funded). *Introduction to Qualitative Interviewing.* (7 January 2016).
ESRC Funded (London). *Interpreting and Writing Up Your Qualitative Findings*. (5 February 2016).
The University of Manchester. *Practice Skills for Data Analysts & Introduction to Statistics*. (9-10 February 2016).
The University of Kent. *Critical Methods in the Social Sciences: Creativity and Critique*. (15 February 2016).
The University of Hertfordshire. *Comparing groups.* (24 February 2016)

The University of Sussex internal courses (ESRC funded)

Designing research posters (24 November 2015)
Undertaking a Literature Review in the Social Sciences (30 November 2015)
Exploring Ethical Issues in your Research (13 April 2016)
Practical tips to improve your academic writing (16 May 2016)
Using technology to manage your research (25 May 2016)
Building a researcher web presence using social media (1 June 2016)
Presentation design (2 June 2016)
Practical Assertiveness for Researchers (7 June 2016)
Presentation delivery (9 June 2016)
Introduction to Prezi and finding images for your presentations (15 June 2016)
Effective researcher (7 October 2016)
WEBINAR: An Introduction to NVivo (11 October 2016)
Introduction to NVivo 11 (24-25 January 2017)
Writing your thesis in the Social Sciences (13 February 2017)
Finding dissertations and theses for your research (17 February 2018)
Introduction to R - Part 1 (6 March 2017)
Introduction to R - Part 1 (13 March 2017)
Making Progress in your Doctorate (16 March 2017)
Editing your thesis (16 March 2017)
MindView 6 – Get started with Mind Mapping (17 March 2017)
Keeping up to date in your subject (18 May 2017)
Managing your research data (21 June 2017)
Take 5: Digital productivity for researchers (06 November 2017)
Communicating your research to non-specialists (and the Three Minute Thesis) (01 December 2017)
Boosting Your Productivity: Time Management for Busy Researchers (09 March 2018)
Preparing for your final year (02 May 2018)
WEBINAR: Preparing for your viva (Arts & Humanities and Social Sciences) (22 May 2018)

Festival of Doctoral Research: Opening talks - From Reactive to Proactive: Reimagining mental health for doctoral researchers (26 June 2018)
Festival of Doctoral Research: Research Image Competition Exhibition (27 June 2018)
Thesis Boot Camp (27-29 July 2018)

(University of Sussex research modules (ESRC funded))
Research Design and Ethics (Spring Semester 15/16)
Action Research (Spring Semester 16/17)
Evidence for Policy and Practice: A Critical Stance (Spring Semester 16/17)
Systematic Review (Summer Teaching 16/17)
Effective Research Data Management (Summer Teaching 16/17)
Social Inclusion in Education and Social Care (Summer Teaching 16/17)
Introduction to Quantitative Methods (Autumn Semester 16/17)
Introduction to Qualitative Methods (Autumn Semester 16/17)
Philosophy of Science and Social Science Research Practice (Autumn Semester 17/18)
Self, Voice and Creativity in Research Writing (Spring Semester 17/18)

Seminars
Clarke, Rachel (2016). *Quality of life and wellbeing in working carers.* Dementia Research Seminar: Brighton and Sussex Medical School, University of Sussex.
Clarke, Rachel (2017). *Wellbeing, Work And Life Balance, Working Family Carers Of People With Dementia: A Review. in:* NHS Sussex Partnership, NHS Foundation Trust: Dementia Seminar, Sussex Education Centre, Hove.
Clarke, Rachel (2018). *The experience of the everyday life of dementia working carers: Sustaining work-life reconciliation.* Dementia Research Seminar: Brighton and Sussex Medical School, University of Sussex.

Conferences
Clarke, Rachel (2017). *Exploring psychological wellbeing in working dementia carers*. In: AAIC 2017 London. Alzheimer's Association International Conference.
Clarke, Rachel (2018). *The experience of the everyday life of dementia working carers: Sustaining work-life reconciliation.* SPA Annual Conference.

Other
Clarke, Rachel (2015). *Work and life balance among working family carers of a Person with Dementia.* Clinical Research Network. Kent Surrey and Sussex: Ageing Specialty Meeting- Poster Presentation (first prize).

Journal publication
Clarke, R., Farina, N., Chen, H.L. & Rusted J.M. in collaboration with the IDEAL Study research team. (2018) Quality of life and wellbeing of carers of people with dementia: are there differences between working and non-working carers? Results from the IDEAL Study. Research article submitted for publication.

Appendix II:

Recruitment email

Dear all,

re: Exploring the work-life balance of working family carers of a person with dementia (for further information please see the attached Project Information Sheet)

If you or someone you know:

- Live with older people with dementia but NOT frontotemporal dementia?
- Work on a voluntarily or paid basis for at least 10 hours per week?
- Provide care for at least 10 hours per week? AND
- Have had a minimum of 1 year in the caring role?

AND you are interested in my research study, please contact me via rc362@sussex.ac.uk

My name is Rachel Clarke and I am a second year PhD student who been supervised by Dr. Henglien Lisa Chen (h.l.chen@sussex.ac.uk), School of Education and Social Work; and Prof. Jennifer Rusted (j.rusted@sussex.ac.uk), School of Psychology. The research is project linked to the 'Improving the experience of Dementia and Enhancing Active Life (IDEAL)' study and is funded by the Economic and Social Research Council (ESRC) and the National Health Research Council (NHRC). It has the IRAS research ethic approval as part of the Health Research Authority's work.

The research aims to develop a model of sustainable work and life balance which assists in the development of services and support for dementia working family carers in the UK. I look forward to hearing from you.

Thank you in advance for your consideration and support,

Kind regards

Rachel Clarke
PhD student
School of Education and Social Work
University of Sussex
Email: rc362@sussex.ac.uk
Mobile: 07902 651500

Appendix III:

Recruitment poster

University of Sussex

Improving Dementia Care ESRC·NIHR

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Living well with dementia: Sustaining psychological wellbeing in working family carers

University of Sussex - *Rachel Clarke, Dr Henglien Lisa Chen (Social Work & Social Care), Prof. Jennifer Rusted (Psychology)*

DO YOU OR ANYONE YOU KNOW WORK AND CARE FOR A PERSON WITH DEMENTIA?

We need people like you to take part in an exciting new study which is exploring the work life balance among working carers.

If you meet the criteria below, and are interested in participating in this project, please tear off a strip below to contact Rachel Clarke (rc362@sussex.ac.uk or 07902 651500) who will provide you with more information:

- ✓ I work (voluntarily or paid) and provide care for at least 10 hours a week
- ✓ I have had a minimum of one years' experience as a carer
- ✓ I do not provide care for a person with frontotemporal dementia

rc362@sussex.ac.uk or call 07902 651500
rc362@sussex.ac.uk or call 07902 651500
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Appendix IV:

Introductory email

Dear xxx,

My name is Rachel Clarke and I'm working on a study called **Working carers living well with dementia: Sustaining wellbeing through work-life reconciliation** at the University of Sussex. I am emailing you as you have shown interest in participating in this study. I have attached the Participant Information Sheet (Summary) for you to read though so you can get a better idea of the study procedure.

I look forward to hearing from you.

Kind regards

Rachel Clarke
PhD student
School of Education and Social Work
University of Sussex
Email: rc362@sussex.ac.uk
Mobile: 07902 651500

Appendix V:

Participant Information Sheet Summary

IRAS: 203695

This research is being undertaken towards a PhD qualification

Participant Information Sheet Summary

Living Well with Dementia: Sustaining psychological wellbeing in working family carers (Rachel Clarke, BSc, MSc)

What is the purpose of the study? This study aims to identify the factors associated with sustainable work and life balance in working family carers.

Why have I been invited? You have been identified because you fulfill the criteria for the study and you have registered an interest in research participation with Sussex Partnership Trust.

Do I have to take part? No. If you agree to take part, you will be fully informed of the nature of the study and be asked to sign two consent forms.

What will happen to me if I take part? The first stage of the study will be completed between you and me, the researcher, in your home or public environment over two stages. I will ask you questions which have been used in other studies and provide an overall measure of: your sense of wellbeing; your everyday functioning; your work and life balance; and the everyday functioning of the person you are providing care for. This will take about 1.5 to 2 hours. Stage 2 will take place about two weeks after our first meeting. Through questions and answers it will explore more about your work and life balance, and will take about 1.5 to 2 hours. Stage 2 will need to be audio recorded in order to be transcribed efficiently. Transcription will be performed by the main researcher – Rachel Clarke. Recordings will be securely stored in archived folder for a maximum of 5 years following completion, and then securely deleted.

What are the possible disadvantages and risks of taking part? There may be some risk of emotional distress by taking part in this study. If you feel uncomfortable during the interview, we can pause the session or completely stop. You can also refuse to answer any questions that you would prefer not to. If you

do feel significant distress during the study, we will recommend that you contact your GP in the first instance. In any event, you will be supplied with a guidance sheet of supportive services.

What are the benefits of taking part? Your input would enable us to gain a better understanding of how working family carers of a person with dementia sustain their work and life balance, where there is very little awareness in research and in the public domain.

Will my taking part in the study be kept confidential? All information you provide will be handled in confidence within the research team and will be anonymised. If in the course of our discussions you expressed views that made me have *significant* concerns for your mental or physical wellbeing, only then do I have the responsibility in line with good research practice to inform a designated professional who would talk to you and offer appropriate support and protection.

What will happen to the results of the research? You will receive a written summary of the overall findings at the end of the research study. The outcomes will be anonymised and published in a PhD thesis and in relevant research journals.

What will happen if I don't want to carry on with the study? You are free to withdraw from the study up to the point of data analysis. You also have the right to request that your data is withdrawn from the study and destroyed. Although we will be unable to withdraw data that has been included in published material, you are assured that your identity will remain anonymous.

What if there is a problem? If you have any concerns about participating in the study, please contact: Sussex Partnership's Patient Advice and Liaison Service, Arundel Road, Worthing, West Sussex BN13 3EP; Tel: 0300 304 2198; Email: pals@sussexpartnership.nhs.uk

Appendix VI:

IDEAL Main Study Data Request Form

Name of trial: ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

IDEAL Main Study Data Request Form

This form should be approved by the CI (Linda Clare) for the data request to be fulfilled. This process allows the trial management team to keep track of versions of the data that have been released and for what purpose.

Once the requestor section is complete, please send to Sharon Nelis S.M.Nelis@exeter.ac.uk, who can sign off the request after consulting with Linda Clare. Once approved, forward to Cathy Blakey, cathy.blakey@bangor.ac.uk at NWORTH. The requestor must allow adequate time for the data request form to be processed. Please allow a minimum of 2 weeks for any request.

Please leave the NWORTH section blank.

Requestor section

Name of person requesting data:	Rachel Clarke
Date of request	05/06/2017
What is the data being requested for? (Please provides specific details of request)	PhD linked studentship
Time point/s requested	1 ☒ 2 ☐ 3 ☐

Study Protocol v2.docx

Based on the protocol provided by Rachel Clarke Linda Clare (CI of IDEAL) has restricted the data request to include carers of working age (i.e. carers aged below 65) and carers who report that they are currently in employment only. The measures listed below will be provided for cases meeting these criteria.

Tick all that are required	Questionnaire title or measure acronym	Additional comments
Participant Part 1		
☐	P1 Coversheet	
☐	P1 MMSE	
☒	P1 Researcher	Diagnosis, date of diagnosis, diagnosis confirmed?, Q6. what is the relationship between PwD and carer?
☐	P1 Information about you	
☐	P1 Education	
☐	P1 Employment	
☐	P1 Religious beliefs	
☐	P1 Spirituality	
☐	P1 Health	
☐	P1 Health State	
☐	P1 Life events	
☐	P1 Diet	
☐	P1 Alcohol	
☐	P1 Smoking	
☐	P1 Pets	
☐	P1 Your accommodation	
☐	P1 Society and community	
☐	P1 Field Notes or comments	
Relative/Friend Part 1		
☐	C1 Coversheet	
☒	C1 Information about you	Q2 – 4, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17. All information possible relating to demographics i.e. age, dob, ethnic group, gender, main language, relationship to PwD (length of time knowing them), time spent caring in a day Q5, Q6, Q13 not relevant
☒	C1 Education	Q21 – correlates to our demographic question on educational level
☒	C1 Employment	All – for assessment of working and non-working carers
☐	C1 Religious beliefs	
☐	C1 Spirituality	

Tick all that are required	Questionnaire title or measure acronym	Additional comments
☐	C1 Health	
☒	C1 Health state	EQ-5D-3L Q45 – 50 Will complement our findings on physical and mental (e.g. depression) health
☒	C1 Life events	All & Q52
☐	C1 Alcohol	
☐	C1 Smoking	
☐	C1 Information about memory problems	
☐	C1 Your accommodation	
☒	C1 Society and community	
☐	C1 Field notes or comments	
Participant Part 2		
☐	P2 Coversheet	
☐	P2 ACE – III	
☐	P2 Researcher	
☐	P2 Interests and activities	
☐	P2 Attitudes to ageing	
☐	P2 Mood	
☐	P2 Quality of life	
☐	P2 Sleep	
☐	P2 WHO-5 Well-Being Index	
☐	P2 Social participation	
☐	P2 Self-efficacy	
☐	P2 Satisfaction with life	
☐	P2 Social networks	
☐	P2 Relationship Quality - current	
☐	P2 Relationship Quality – retrospective	
☐	P2 Everyday activities	
☐	P2 Difficulties that you may experience (RADIX)	
☐	P2 Stigma	
☐	P2 Information about the condition	
☐	P2 Optimism	
☐	P2 Sense of self	

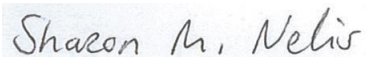
Tick all that are required	Questionnaire title or measure acronym	Additional comments
☐	P2 Loneliness scale	
☐	P2 Rosenberg Self-Esteem Scale	
☐	P2 Your comments	
☐	P2 FAST	
☐	P2 Global Deterioration Scale	
☐	P2 Field notes or comments	
Relative/Friend Part 2		
☐	C2 Coversheet	
☐	C2 Your relative's/friend's quality of life	
☐	C2 Your relative's/friend's well-being	
☐	C2 How your relative/friend spends his/her time	
☐	C2 Your relative's/friend's satisfaction with life	
☐	C2 Difficulties that your relative/friend may experience	
☒	C2 Your relative's/friend's everyday activities	Correlate to questionnaires used in our study (Functional Activities Questionnaire & Dependence Scale)
☐	C2 Your relative's/friend's emotional well-being	
☒	C2 Support from others	Q89 – 94. Lubben Social Network Scale-6; Correlates to COPE questions regarding instrumental and emotional support
☐	C2 Your current relationship	
☐	C2 Your past relationship	
☒	C2 Your physical health	General Practice Physical Activity Questionnaire (GPPAQ) - Q118 - 124 & Q125 (subjective age). Supplementary questions to SF-12 (physical health questions used in this study) – Q118 specifically focuses on physical activity involved in work.
☒	C2 Your well-being	Q126 – Q130 WHO-5. Used in this study
☒	C2 Your quality of life	WHO-QOL BREF Q131 – 156.
☒	C2 How you feel about yourself	Rosenberg Self-Esteem Scale Q157 - 166 - will compliment our

Tick all that are required	Questionnaire title or measure acronym	Additional comments
		findings (we are not asking about self-esteem)
☐	C2 Your satisfaction with life	
☒	C2 How you see yourself	Generalized Self-Efficacy Scale – correlates with COPE.
☒	C2 Your mood	Q209–228 (CESD-R). Questions relevant to depression used in our study (shorter version of CESD-R-10)
☒	C2 Your experiences of supporting	Question relevant to coping (229), (Q230 – 232 - Role captivity), Q233-234 Modified Social Restriction Scale, caregiving competence Q235-237, Q238–252 Relative Stress Scale, positive aspects of caregiving Q253–261.
☒	C2 How you are managing	Questions relevant to management used in our study (management of situation) Q262 – 265
☐	C2 Field notes or comments	
Participant Part 3		
☐	P3 Coversheet	
☐	P3 Section A	
☐	P3 Physical health	
☐	P3 Dignity and respect	
☐	P3 Psychological Well-Being	
☐	P3 Personality	
☐	P3 Green/blue spaces	
☐	P3 Social capital	
☐	P3 Social activities	
☐	P3 Cultural activities	
☐	P3 Available resources (Resource Generator)	
☐	P3 Health conditions	
☐	P3 Sources of income	
☐	P3 Household income	
☐	P3 Service use	
☐	P3 Community health and care	
☐	P3 Home help	

Tick all that are required	Questionnaire title or measure acronym	Additional comments
☐	P3 Community services	
☐	P3 Accommodation away from home	
☐	P3 Equipment and adaptions	
☐	P3 Help and support	
☐	P3 Medication	
☐	P3 Travel costs	
☐	P3 Satisfaction with health services	
☐	P3 Field notes or comments	
Relative/Friend Part 3		
☐	C3 Coversheet	
☐	C3 Your relative's/friend's background	
☐	C3 Your relative's/friend's employment/job	
☐	C3 Your relative's/friend's health	
☐	C3 Your relative's/friend's health state	
☐	C3 Your relative's/friend's emotions	
☐	C3 Your relative's/friend's support network	
☐	C3 Your relative's/friend's accommodation	
☐	C3 Your relative's/friend's interests	
☐	C3 Your relative's/friend's entertainment	
☐	C3 Your relative's/friend's involvement	
☐	C3 Dignity and respect	
☐	C3 Your relative's/friend's life events	
☐	C3 Your health conditions	
☐	C3 Your neighbourhood	
☐	C3 Your social activities	
☐	C3 Your entertainment activities	
☐	C3 Resources available to you from others	
☐	C3 Your views	
☐	C3 Field notes and comments	

Approval section

Approval given ☒

Signature:  Date: 04/07/17

NWORTH section

A copy of all data extracted and issued to be made available to the Study team Statistician Yu-Tzu Wu Y.Wu3@exeter.ac.uk.

Person who completed data request:	Click here to enter text.
Date of data issue:	Click here to enter a date.
Location of extracted files:	Click here to enter text.
Redmine ticket number:	Click here to enter text.
MD5/sha1 of file(s):	Click here to enter text.

Appendix VII:

Information sheet for selecting an object for the semi-structured interview

Information Sheet for second visit

You are free to withdraw from the study at any time and without giving a reason. You also have the right to request that your data is withdrawn from the study and destroyed.

Study instructions for Stage 2 – Stage 2 of the study is designed to explore your experience of balancing work and care and will last for around 1.5 – 2 hours. In preparation for this interview, I would like you to select an object of personal significance which you feel supports the work and life balance. There are no restrictions to the type of object you select. For example, photographs and objects representing multiple areas which assist the work and life balance are acceptable, as long as one item is selected.

I will begin the interview by asking: 'Please discuss the object you have chosen to represent the work and life balance'

Please discuss your selected object freely. I may ask some questions relating to clarification of something you have said or to ask you to elaborate on a subject further. The interview will be focused on exploring:

i. how you balance work and care
ii. the conflicts you experience between work and care
iii. the support you currently receive which assists with the work and life balance
iv. other support you feel would assist with the work and life balance
v. what recommendations you would make to policy makers to help working family carers like you

If you have any questions about how to select an object or any other aspect of the interview, I will be happy to go through them with you.

The interview date has been arranged for: _____

Contact Details:
Rachel Clarke (researcher) rc362@sussex.ac.uk 07902 651500
Dr Henglien Lisa Chen (first supervisor) h.l.chen@sussex.ac.uk 01273 873721
Professor Jennifer Rusted (second supervisor) j.rusted@sussex.ac.uk 01273 678325

Appendix VIII:

Follow-up letter

Rachel Clarke (PhD Student)
Essex House
University of Sussex
Brighton
Falmer
BN1 9RH

Tel: 07902 651500
Email: rc362@sussex.ac.uk

Date:

PRIVATE & CONFIDENTIAL

Dear

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

I am writing to you to thank you for your participation in the first stage of this study. As arranged, the second stage of this study will take place on_____.

If you are still happy to take part in the second stage of the study, would you please complete the attached Informed Consent Form and Photography Consent Form once you have read the Participant Information Sheet Summary and return both.

For this session, I would like you to select an object of personal significance which you feel supports the work and life balance. If you have any questions about how to select an object or any other aspect of the interview, please contact me using the contact details above and I will be happy to go through them with you.

Thank you for your much valued contribution to this research, and I look forward to meeting with you again soon.

Yours sincerely

Rachel Clarke,
PhD Student

Enc.

Appendix IX:

Questionnaire (primary cohort)

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

Face-to-face questionnaire

[Verbal instruction]: You are free to choose not to answer any of the questions posed, or to withdraw from the study at any time and without giving a reason. You also have the right to request that your data is withdrawn from the study and destroyed.

Study instructions for Stage 1 (face to face questionnaires) - The first stage of the study will last about one and a half hours to two hours. I will begin firstly, by asking you a short set of questions which enable me to understand a little more about your background, your caring responsibilities and your occupation. Secondly, I will ask questions about your wellbeing; your everyday functioning, which includes a short computer task; the everyday functioning of the person you provide care for, and your work and life balance. The questions I will ask you comprise a series of questionnaires which have been validated with participants in other studies, and they explore how participants feel about various situations. For each section, I will briefly explain to you what is being explored. As all questions are part of standardised questionnaires which individually create a total score, I will ask all questions as they are shown on the questionnaires. Although you may feel that some questions do not apply to your current situation, please attempt to answer all questions. If there are any questions you would prefer not to answer, then you don't have to answer them. If there are any questions I ask that are not clear, please let me know and I will explain them in further detail.

At the end of stage 1, I will arrange a time that is convenient to you for a further visit for stage 2 which will be explained in more detail at the end of this interview.

Stage I

ID number:……

Information about you

The questions in this part are designed to find out more about your background, your caring responsibilities and your occupation. This information will be used to get a better understanding of the demographic characteristics of working family carers of a person with dementia in this study and the similarities and differences across cases.

Q1. Gender

Male ☐ Female ☐

Do you, or have you ever considered yourself as Transgender? YES ☐ NO ☐

Q2. Date of birth (dd/mm/yyyy)

☐☐☐☐☐☐☐☐

Q3. What is your ethnic group?

White: English/Welsh/Scottish/Northern Irish/British ☐
White: Irish ☐
White: Gypsy or Irish Traveller ☐
Mixed White & Black: Caribbean ☐
Mixed White & Black: African ☐
Mixed White & Asian ☐
Asian/Asian British: Indian ☐
Asian/Asian British: Pakistani ☐
Asian/Asian British: Bangladeshi ☐
Asian/Asian British: Chinese ☐
Black/Black British: African ☐
Black/Black British: Caribbean ☐
Arab ☐

Any other ethnic group; please specify:

……

Q4. What is your relationship to the person you provide care for?

Spouse (husband/wife) ☐
Partner ☐
Son/daughter ☐
Son/daughter-in-law ☐
Step-child ☐
Niece/nephew ☐
Brother/Sister ☐

Other; please specify

……

Q5. Please provide (best estimate) in years, the length of time you have been providing care for your [use appropriate term].

……

Q6. What is the diagnosis of your [use appropriate term]?

Alzheimer's disease ☐
Vascular dementia ☐
Mixed (Alzheimer's & Vascular) ☐
Parkinson's disease dementia ☐
Lewy body dementia ☐
Unspecified dementia ☐

Other; please specify

……

Q7. When were they diagnosed (best estimate)? (dd/mm/yyyy)

☐☐☐☐☐☐☐☐

Q8. On a typical day, how much time do you spend looking after/providing care for your [use appropriate term]?

More than 1 hour and up to 2 hours ☐
More than 2 hours and up to 3 hours ☐
More than 3 hours and up to 5 hours ☐
More than 5 hours and up to 10 hours ☐
More than 10 hours, but not overnight ☐
More than 10 hours and/including overnight ☐

Other; please describe:

……

Q9. Do you provide care for anyone else?

Sibling ☐
Child/ren ☐
Grandchild/ren ☐
Friend/s ☐

Other; please specify

……

Q10. Roughly, how often do you provide care for [insert here]?

……

Q11. Tell me about your education
What was the highest level qualification you sat?

No formal qualifications ☐
GCSEs or equivalent (O levels, CSEs, School Certificate, Standard Grades) ☐
Completed apprenticeship ☐
A levels or equivalent (Leaving Certificate, Higher Grades) ☐
National Vocational Qualification ☐
Higher National Diploma ☐
Undergraduate degree (BA, BSc) ☐
Master's degree (MA, MSc) ☐
PhD ☐

Other; please specify

……

Q12. Which of the following best describes your current employment situation?

In paid employment (including self-employment/business owner) ☐
Doing voluntary (unpaid) work ☐
Or some mixture? – please explain…… ☐

Q13. What is your occupation?

……

Q14. What type of work is this? (i.e. administrative/manual/strategic)

……

Q15. How long have you been in this role (months or years)?

……

Q16. How many hours do you work per week?

……

Q17. Is your contract (select all that apply):

Self-employed? ☐
Part-time? ☐
Full-time? ☐
Flexible? ☐
Permanent? ☐
Fixed-term? ☐
Freelance? ☐
Zero hours? ☐

Q18. What is your average salary per month?

£500 - £1000 ☐
£1500 - £2000 ☐
£2500 - £3000 ☐
More than £3000 ☐
Prefer not to say ☐

Q19. Have you reduced your working hours in order to provide care for your [use appropriate term]

No ☐
Yes, reduced ☐

If yes, by how many hours per week have you reduced your working hours?……..

Part A: Psychological wellbeing

The questions in this section are designed to find out more about your psychological wellbeing, your general health and how you are coping. Please be as honest and accurate as you can. There are no "right" or "wrong" answers. All questions require one answer only. Please attempt to answer all questions but if there are any questions you would prefer not to answer, please state 'pass' and I will move onto the next question. (For each instrument, researcher holds up card with relevant response options).

WHO-5 Well-Being Index

Please indicate for each of these statements how you have been feeling in the last 4 weeks.

A1. I have felt cheerful and in good spirits.

- All of the time ☐
- Most of the time ☐
- More than half of the time ☐
- Less than half of the time ☐
- Some of the time ☐
- At no time ☐

A2. I have felt calm and relaxed.

- All of the time ☐
- Most of the time ☐
- More than half of the time ☐
- Less than half of the time ☐
- Some of the time ☐
- At no time ☐

A3. I have felt active and vigorous.

- All of the time ☐
- Most of the time ☐
- More than half of the time ☐
- Less than half of the time ☐
- Some of the time ☐
- At no time ☐

A4. I woke up feeling fresh and rested.

- All of the time ☐
- Most of the time ☐
- More than half of the time ☐
- Less than half of the time ☐
- Some of the time ☐
- At no time ☐

A5. My daily life has been filled with things that interest me.

- ☐ All of the time
- ☐ Most of the time
- ☐ More than half of the time
- ☐ Less than half of the time
- ☐ Some of the time
- ☐ At no time

The Short-Form Health Survey (SF-12)

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

A6. In general, would you say your health is….

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

A7. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

- ☐ YES, limited a lot
- ☐ YES, limited a little
- ☐ NO, not limited at all

A8. Climbing several flights of stairs.

- ☐ YES, limited a lot
- ☐ YES, limited a little
- ☐ NO, not limited at all

During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

A9. Accomplished less than you would like.

- ☐ YES
- ☐ NO

A10. Were limited in the kind of work or other activities.

- ☐ YES
- ☐ NO

During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

A11. Accomplished less than you would like.

- ☐ YES
- ☐ NO

A12. Did work or activities less carefully than usual.

- ☐ YES
- ☐ NO

A13. During the past 4 weeks how much did pain interfere with your normal work (including work outside the home and housework)?

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

These questions are about how you have been feeling during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks;

A14. Have you felt calm & peaceful?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

A15. Did you have a lot of energy?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

A16. Have you felt down-hearted and blue?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

A17. During the past 4 weeks how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

The Center for Epidemiologic Studies Depression Scale Revised (CESD-R-10)

The questions I am about to ask list some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week. Some or all of these statements may not apply to you, but please attempt to answer questions as best as you can.

A18. I was bothered by things that usually don't bother me

- ☐ Rarely or none of the time (less than 1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of time (3-4 days)
- ☐ All of the time (5-7 days)

A19. I had trouble keeping my mind on what I was doing

- ☐ Rarely or none of the time (less than 1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of time (3-4 days)
- ☐ All of the time (5-7 days)

A20. I felt depressed

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A21. I felt that everything I did was an effort

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A22. I felt hopeful about the future

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A23. I felt fearful

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A24. My sleep was restless

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A25. I was happy

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A26. I felt lonely

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

A27. I could not get going

- Rarely or none of the time (less than 1 day) ☐
- Some or a little of the time (1-2 days) ☐
- Occasionally or a moderate amount of time (3-4 days) ☐
- All of the time (5-7 days) ☐

Role Captivity Scale

Here are some thoughts and feelings that people sometimes have about themselves as carers. Please answer the questions in relation to your relationship with your relative/friend.. How much does each statement describe your thoughts about your role as a carer?

A28. How much do you wish you were free to lead a life of your own?

- Not at all ☐
- Just a little ☐
- Somewhat ☐
- Very much ☐

A29. How much do you feel trapped by your relative's/friend's memory, thinking or behaviour difficulties?

- Not at all ☐
- Just a little ☐
- Somewhat ☐
- Very much ☐

A30. How much do you wish you could just run away?

- Not at all ☐
- Just a little ☐
- Somewhat ☐
- Very much ☐

Caregiving Competence Scale

A31. How often do you feel confident that you are meeting the needs of your relative/friend?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

A32. How often do you feel that you are doing a good job as a carer?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

A33. How often do you feel competent in your ability to care for your relative/friend?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

Management of Situation Scale

Here are some things that people do to make caring easier for themselves. How often do you behave in these ways?

A34. How often do you try to be firm in directing your relative's/friend's behaviour?

- ☐ Never
- ☐ Once in a while
- ☐ Fairly often
- ☐ Very often

A35. How often do you do things you really have to do and let the other things slide?

- ☐ Never
- ☐ Once in a while
- ☐ Fairly often
- ☐ Very often

A36. How often do you try to find ways to keep your relative/friend busy?

- ☐ Never
- ☐ Once in a while
- ☐ Fairly often
- ☐ Very often

A37. How often do you try to learn as much as you can about memory, thinking or behaviour difficulties (e.g. read books, talk to doctors, go to lectures)?

- Never ☐
- Once in a while ☐
- Fairly often ☐
- Very often ☐

The Short Zarit Burden Interview

The questions I am about to ask are related to the stressors associated with the caring role which many carers have experienced at one time or another. Some or all of these statements may not apply to you, but please attempt to answer questions as best as you can.

DO YOU FEEL . . .

A38. that because of the time you spend with your relative that you don't have enough time for yourself?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A39. stressed between caring for your relative and trying to meet other responsibilities (work/family)?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A40. angry when you are around your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A41. that your relative currently affects your relationship with family members or friends in a negative way?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A42. strained when you are around your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A43. that your health has suffered because of your involvement with your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A44. that you don't have as much privacy as you would like because of your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A45. that your social life has suffered because you are caring for your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A46. that you have lost control of your life since your relative's illness?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A47. uncertain about what to do about your relative?

- Never ☐
- Rarely ☐
- Sometimes ☐
- Quite frequently ☐
- Nearly always ☐

A48. that you should be doing more for your relative?

Never	☐
Rarely	☐
Sometimes	☐
Quite frequently	☐
Nearly always	☐

A49. that you could do a better job in caring for your relative?

Never	☐
Rarely	☐
Sometimes	☐
Quite frequently	☐
Nearly always	☐

The Brief COPE Index

The following questions deal with the caring role. Obviously, different carers deal with caring in different ways, but I am interested in how you deal with caring. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Try to rate each item separately in your mind from the others.

A50.I've been turning to work or other activities to take my mind off things.

I haven't been doing this at all	☐
I've been doing this a little bit	☐
I've been doing this a medium amount	☐
I've been doing this a lot	☐

A51. I've been concentrating my efforts on doing something about the situation I'm in.

I haven't been doing this at all	☐
I've been doing this a little bit	☐
I've been doing this a medium amount	☐
I've been doing this a lot	☐

A52. I've been saying to myself "this isn't real.".

I haven't been doing this at all	☐
I've been doing this a little bit	☐
I've been doing this a medium amount	☐
I've been doing this a lot	☐

A53. I've been using alcohol or other drugs to make myself feel better.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A54. I've been getting emotional support from others.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A55. I've been giving up trying to deal with it.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A56. I've been taking action to try to make the situation better.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A57. I've been refusing to believe that it has happened.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A58. I've been saying things to let my unpleasant feelings escape.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A59. I've been getting help and advice from other people.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A60. I've been using alcohol or other drugs to help me get through it.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A61. I've been trying to see it in a different light, to make it seem more positive.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A62. I've been criticizing myself.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A63. I've been trying to come up with a strategy about what to do.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A64. I've been getting comfort and understanding from someone.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A65. I've been giving up the attempt to cope.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A66. I've been looking for something good in what is happening.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A67. I've been making jokes about it.

I haven't been doing this at all ☐
I've been doing this a little bit ☐
I've been doing this a medium amount ☐
I've been doing this a lot ☐

A68. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A69. I've been accepting the reality of the fact that it has happened.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A70. I've been expressing my negative feelings.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A71. I've been trying to find comfort in my religion or spiritual beliefs.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A72. I've been trying to get advice or help from other people about what to do.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A73. I've been learning to live with it.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A74. I've been thinking hard about what steps to take.

- ☐ I haven't been doing this at all
- ☐ I've been doing this a little bit
- ☐ I've been doing this a medium amount
- ☐ I've been doing this a lot

A75. I’ve been blaming myself for things that happened.

- ☐ I haven’t been doing this at all
- ☐ I’ve been doing this a little bit
- ☐ I’ve been doing this a medium amount
- ☐ I’ve been doing this a lot

A76. I've been praying or meditating.

- ☐ I haven’t been doing this at all
- ☐ I’ve been doing this a little bit
- ☐ I’ve been doing this a medium amount
- ☐ I’ve been doing this a lot

A77. I've been making fun of the situation.

- ☐ I haven’t been doing this at all
- ☐ I’ve been doing this a little bit
- ☐ I’ve been doing this a medium amount
- ☐ I’ve been doing this a lot

Part B: Your everyday functioning

The following series of questions are about your everyday functioning. Please be as honest and accurate as you can. There are no "right" or "wrong" answers. All questions require one answer only. Please attempt to answer all questions but if there are any questions you would prefer not to answer, please state ‘pass’ and I will move onto the next question. (For each instrument, researcher holds up card with relevant response options).

Cognitive Failures Questionnaire

The following series of questions are about minor mistakes which everyone makes from time to time. We want to know how often these things have happened to you in the past four weeks.

B1. Do you read something & find you haven’t been thinking about it and must read it again?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B2. Do you find you forget why you went from one part of the house to the other?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B3. Do you fail to notice signposts on the road?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B4. Do you find you confuse right and left when giving directions?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B5. Do you bump into people?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B6. Do you find you forget whether you've turned off a light or a fire or locked the door?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B7. Do you fail to listen to people's names when you are meeting them?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B8. Do you say something and realize afterwards that it might be taken as insulting?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B9. Do you fail to hear people speaking to you when you are doing something else?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B10. Do you lose your temper and regret it?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B11. Do you leave important letters unanswered for days?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B12. Do you find you forget which way to turn on a road you know well but rarely use?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B13. Do you fail to see what you want in a supermarket (although it's there)?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B14. Do you find yourself suddenly wondering whether you've used a word correctly?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B15. Do you have trouble making up your mind?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B16. Do you find you forget appointments?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B17. Do you forget where you put something like a newspaper or a book?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B18. Do you find you accidentally throw away the thing you want and keep what you meant to throw away – as in the example of throwing away the matchbox and putting the used match in your pocket?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B19. Do you daydream when you ought to be listening to something?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B20. Do you find you forget people’s names?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B21. Do you start doing one thing at home and get distracted into doing something else (unintentionally)?

- [ ] Very often
- [ ] Quite often
- [ ] Occasionally
- [ ] Very rarely
- [ ] Never

B22. Do you find you can't quite remember something although it's "on the tip of your tongue"?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B23. Do you find you forget what you came to the shops to buy?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B24. Do you drop things?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

B25. Do you find you can't think of anything to say?

- Very often ☐
- Quite often ☐
- Occasionally ☐
- Very rarely ☐
- Never ☐

Attentional Control Scale

Please read the following statements carefully and reflect on how much they represent your behaviour over the past 4 weeks. Respond to each question which is on a scale from 1 to 4, with 1 meaning this statement almost never applies to you, and 4 meaning this statement always applies to you.

B26. It is hard for me to break from one way of thinking about something and look at it from another point of view.

Almost never 1————————2————————3————————4 Always

B27. After being interrupted or distracted, I can easily shift my attention back to what I was doing before.

Almost never 1————————2————————3————————4 Always

B28. I can quickly switch from one task to another.

Almost never 1————————2————————3————————4 Always

B29. When I need to concentrate and solve a problem, I have trouble focusing my attention.

Almost never 1————————2————————3————————4 Always

B30. It is easy for me to read or write while I'm also talking on the phone.

Almost never 1————————2————————3————————4 Always

B31. I have a hard time concentrating when I'm excited about something.

Almost never 1————————2————————3————————4 Always

B32. It's very hard for me to concentrate on a difficult task when there are noises around.

Almost never 1————————2————————3————————4 Always

B33. I can become interested in a new topic very quickly when I need to.

Almost never 1————————2————————3————————4 Always

B34. My concentration is good even if there is music in the room around me.

Almost never 1————————2————————3————————4 Always

B35. When concentrating, I can focus my attention so that I become unaware of what's going on in the room around me.

Almost never 1————————2————————3————————4 Always

B36. When concentrating I ignore feelings of hunger or thirst.

Almost never 1————————2————————3————————4 Always

B37. I have a hard time coming up with new ideas quickly.

Almost never 1————————2————————3————————4 Always

B38. It is easy for me to alternate between two different tasks.

Almost never 1——————2——————3——————4 Always

B39. When I am reading or studying, I am easily distracted if there are people talking in the same room.

Almost never 1——————2——————3——————4 Always

B40. I have trouble carrying on two conversations at once.

Almost never 1——————2——————3——————4 Always

B41. When a distracting thought comes to mind, it is easy for me to shift my attention away from it.

Almost never 1——————2——————3——————4 Always

B42. When I am working hard on something, I still get distracted by events around me.

Almost never 1——————2——————3——————4 Always

B43. It is difficult for me to coordinate my attention between the listening and writing required when taking notes during lectures.

Almost never 1——————2——————3——————4 Always

B44. When trying to focus my attention on something, I have difficulty blocking out distracting thoughts.

Almost never 1——————2——————3——————4 Always

B45. It takes me a while to get really involved in a new task.

Almost never 1——————2——————3——————4 Always

Part C: Work and life balance

The following series of questions are about your work and life balance. Please be as honest and accurate as you can. There are no "right" or "wrong" answers All questions require one answer only. Please attempt to answer all questions but if there are any questions you would prefer not to answer, please state 'pass' and I will move onto the next question. (For each instrument, researcher holds up card with relevant response options).

Maslach Burnout Inventory

C1. I feel emotionally drained from my work

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C2. I feel used up at the end of the workday

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C3. I feel fatigued when I get up in the morning and have to face another day on the job

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C4. Working with people all day is really a strain for me

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C5. I feel burned out from my work

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C6. I feel frustrated from my job

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C7. I feel I'm working too hard on my job

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C8. Working with people directly puts too much stress on me

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

C9. I feel like I'm at the end of my rope

- Never ☐
- A few times a year or less ☐
- Once a month or less ☐
- A few times a month ☐
- Once a week ☐
- A few times a week ☐
- Every day ☐

The Job Satisfaction Subscale of the Michigan Organizational Assessment Questionnaire

When answering the following three questions, keep in mind the kind of work you do and the experiences you have had working there.

C10. All in all I am satisfied with my job.

- Strongly agree ☐
- Agree ☐
- Slightly agree ☐
- Neither agree not disagree ☐
- Slightly disagree ☐
- Disagree ☐
- Strongly disagree ☐

C11. In general, I don't like my job.

- Strongly agree ☐
- Agree ☐
- Slightly agree ☐
- Neither agree not disagree ☐
- Slightly disagree ☐
- Disagree ☐
- Strongly disagree ☐

C12. In general I like where I work?

- Strongly agree ☐
- Agree ☐
- Slightly agree ☐
- Neither agree not disagree ☐
- Slightly disagree ☐
- Disagree ☐
- Strongly disagree ☐

Work-Family Conflict Scale

C13. My work keeps me from my family activities more than I would like.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C14. The time I must devote to my job keeps me from participating equally in household responsibilities and activities.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C15. I have to miss family activities due to the amount of time I must spend on work responsibilities.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C16. The time I spend on family responsibilities often interferes with my work responsibilities.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C17. The time I spend with my family often causes me not to spend time in activities with work colleagues that could be helpful to my career.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C18. I have to miss work activities due to the amount of time I must spend on family responsibilities.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C19. When I finish work I am often too frazzled to participate in family activities/ responsibilities.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C20. I am often so emotionally drained when I finish work that it prevents me from contributing to my family.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C21. Due to all the pressures of work, sometimes when I come home I am too stressed to do the things I enjoy.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C22. Due to stress at home, I am often preoccupied with family matters when I am working.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C23. Because I am often stressed from family responsibilities, I have a hard time concentrating on my work.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C24. Tension and anxiety from my family life often weakens my ability to do my job.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C25. The problem-solving behaviours I use in my job are not effective in resolving problems at home.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C26. Behaviour that is effective and necessary for me when I am working would be counterproductive at home.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C27. The behaviours I perform that make me effective at work do not help me to be a better parent and spouse.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C28. The behaviours that work for me at home do not seem to be effective in my work.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C29. Behaviour that is effective and necessary for me at home would be counterproductive in my work.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

C30. The problem-solving behaviours that work for me at home does not seem to be as useful in my work.

Strongly Disagree 1——————2——————3——————4——————5 Strongly Agree

Part D: The everyday functioning of the person with dementia

The following series of questions are about the everyday functioning of the person you provide care for. Please be as honest and accurate as you can. There are no "right" or "wrong" answers. All questions require one answer only. (For each instrument, researcher holds up card with relevant response options).

Functional Activities Questionnaire

D1. Can your relative/friend write cheques, pay bills, and keep financial records?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D2. Can your relative/friend assemble tax records, make out business or insurance papers?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D3. Can your relative/friend shop alone for clothes, household necessities and groceries?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D4. Can your relative/friend play a game of skill (e.g. bridge, chess, cards, crosswords) or work on a hobby (e.g. gardening)?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D5. Can your relative/friend heat water for coffee or tea and turn off the stove?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D6. Can your relative/friend prepare a balanced meal?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D7. Can your relative/friend keep track of current events?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D8. Can your relative/friend pay attention to, understand and discuss a TV programme, book or magazine?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D9. Can your relative/friend remember appointments, family occasions and to take his/her medication?

- Dependent on others
- Requires assistance but can still do the task
- Has difficulty but does by self
- Never did, and would have difficulty now
- Normal (as s/he has always done)
- Never did, but could do now

D10. Can your relative/friend travel out of the immediate local area - driving, arranging to take buses etc.?

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

D11. Is your relative/friend able to use the telephone appropriately (e.g. finding and dialling correct numbers)?

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

Dependence Scale

D12. Does your relative/friend need reminders or advice to manage chores, do shopping, cooking, play games, or handle money?

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

D13. Does your relative/friend need help to remember important things such as appointments, recent events, or names of family or friends?

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

D14. Does your relative/friend need frequent (at least once a month) help finding misplaced objects, keeping appointments, or maintaining health or safety (locking doors, taking medication)?

- ☐ No
- ☐ Yes

D15. Does your relative/friend need household chores done for him/her?

- ☐ No
- ☐ Yes

D16. Does your relative/friend need to be watched or kept company when awake?

No ☐
Yes ☐

D17. Does your relative/friend need to be escorted when outside?

No ☐
Yes ☐

D18. Does your relative/friend need to be accompanied when bathing or eating?

No ☐
Yes ☐

D19. Does your relative/friend have to be dressed, washed, and groomed?

No ☐
Yes ☐

D20. Does your relative/friend have to be taken to the toilet regularly to avoid incontinence?

No ☐
Yes ☐

D21. Does your relative/friend have to be fed?

No ☐
Yes ☐

D22. Does your relative/friend have to be turned, moved, or transferred?

No ☐
Yes ☐

D23. Does your relative/friend wear an incontinence pad or a catheter?

No ☐
Yes ☐

D24. Does your relative/friend need to be tube fed?

No ☐
Yes ☐

Part E: Closing questions

The following series of questions draw on the positive aspects of caregiving, and your personal experience of the caregiving role.

Positive Aspects of Caregiving Scale

Some people say that, despite all the difficulties involved in giving care to a family member or friend with problems in memory, thinking or behaviour, or other health problems, good things have come out of their experience too. Listed below are a few of the good things some people report. Please say how much you agree or disagree with these statements.

E1. Providing help to my relative/friend has made me feel more useful

Disagree a lot ☐
Disagree a little ☐
Neither agree nor disagree ☐
Agree a little ☐
Agree a lot ☐

E2. Providing help to my relative/friend has made me feel good about myself

Disagree a lot ☐
Disagree a little ☐
Neither agree nor disagree ☐
Agree a little ☐
Agree a lot ☐

E3. Providing help to my relative/friend has made me feel needed

Disagree a lot ☐
Disagree a little ☐
Neither agree nor disagree ☐
Agree a little ☐
Agree a lot ☐

E4. Providing help to my relative/friend has made me feel appreciated

Disagree a lot ☐
Disagree a little ☐
Neither agree nor disagree ☐
Agree a little ☐
Agree a lot ☐

E5. Providing help to my relative/friend has made me feel important

Disagree a lot ☐
Disagree a little ☐
Neither agree nor disagree ☐
Agree a little ☐
Agree a lot ☐

E6. Providing help to my relative/friend has made me feel strong and confident

- Disagree a lot ☐
- Disagree a little ☐
- Neither agree nor disagree ☐
- Agree a little ☐
- Agree a lot ☐

E7. Providing help to my relative/friend has enable made me to appreciate life more

- Disagree a lot ☐
- Disagree a little ☐
- Neither agree nor disagree ☐
- Agree a little ☐
- Agree a lot ☐

E8. Providing help to my relative/friend has enable made me to develop a more positive attitude towards life

- Disagree a lot ☐
- Disagree a little ☐
- Neither agree nor disagree ☐
- Agree a little ☐
- Agree a lot ☐

E9. Providing help to my relative/friend has strengthened my relationships with others

- Disagree a lot ☐
- Disagree a little ☐
- Neither agree nor disagree ☐
- Agree a little ☐
- Agree a lot ☐

Questions from the linked 'Living Well with Dementia' study

E10. Have there been any care challenges you have overcome?

- Would you like to tell us about your successful story about being a carer for people with dementia?

E11.What is currently your greatest difficulty or concern in caring your relative/friend?

- What is the impact of this on your own life?

E12. What is your greatest satisfaction in caring for your relative/friend?

- What is the beneficial impact of this for carers like you?

E13. What do you think could be done by the government to help people live well with dementia which will help carers like you?

E14. What do you think could be changed in the local community to enable people with dementia to live well with dementia as so to help carers like you?

Appendix X:

Interviewing schedule with artifact

Before commencing, remind the participant that the interview will be audio recorded.

I. Opening question - Please discuss the object you have chosen:

Prompts

1. Why did you choose the object?
2. How does the object represent your experience as a working family carer?
3. Why did you choose to be a working family carer?

II. Successful examples of work and care balance

1. Coping - How do you manage to combine work and care?
2. Please could you elaborate further on your experiences of successfully combining work and care?

Prompts

2.1. How does having a job help you as a carer?

2.2 How does being a carer help you at work?

2.3. How does combining work and care fulfil you personally?

3. Is there any aspect of work and care that make you happy?

Prompts

3.1. How does being a carer help you to feel happy at work?

3.2. How does your work help you to feel happy as a carer?

3.3. How does combining work and care fulfil your happiness in life?

4. Do you think work and care help you to promote your physical health?

Prompts

4.1 How does being a carer help with your physical health?

4.2 How does your work help with your physical health?

4.3 How does combining work and care help with your physical health?

5. Does work and care help your memory and attention?

Prompts

5.1 How does being as carer help your attention and memory at work?

5.2 How does your work help your attention and memory as a carer?

5.3 How does combining work and care stimulate your attention and memory overall?

III. Work and care conflicts

1. What are the difficulties of combining work and care?

Prompts

3.1 How does having a job impact on you as a carer?

3.2 How does being a carer impact on you at work?

3.3 How does combining work and care impact on you personally?

2. Is there any aspect of work and care that make you feel tired, depressed or burn-out?

Prompts

2.1. How does being a carer make you feel tired, depressed or burn-out at work?

2.2. How does your work make you feel tired, depressed or burn-out as a carer?

2.3. How does combining work and care make you feel tired, depressed or burnt-out in life?

3. Do you have any physical problems caused by work and care?

Prompts

3.1. How does being a carer impact on your physical health?

3.2. How does your work impact on your physical health?

3.3. How does combining work and care impact on your physical health?

4. Does work and care impact your memory and attention?

Prompts

4.1 How does being a carer impact on your attention and memory at work?

4.2 How does your work impact on your attention and memory as a carer?

4.3 How does combining work and care impact your attention and memory overall?

IV. The support receives which assist with the work and life balance

1. Please could you discuss any support received which assists with combining work and care'.
2. What do you think about the amount and type of support received?'
3. How does this support make you feel happier?

Prompts

3.1 How does the support you receive make you feel happier at work? Is there other support that you think may help?

3.2. How does the support you receive make you feel happier as a carer? Is there other support that you think may help?

3.3. How does the support you receive fulfil your happiness in life? Is there other support that you think may help?

4. Does this support help your memory and attention?

Prompts

4.1 How does this support help your attention and memory at work?

4.2 How does this support help your attention and memory as a carer?

4.3 How does support help your attention and memory with both work and care?

IV. Policy

1. What do you think about current government and your employers' policy for working family carers of people with dementia like you?
2. 'What recommendations, would you make to policy makers and your employer to help working family carers like you and why?

V. Closing

1. Would you like to expand on any other areas of work and life balance in dementia care that you feel are important, but have not been discussed?'

CLOSING INSTRUCTIONS:

b) Thank the participant for their time

c) Photograph the object.

d) Offer to send them a summary of the findings in 2018

Appendix XI:

An example of transcripts showing challenges and sustainability

Researcher: Right…Could you please discuss the object that you have chosen?
DWC1: Yes, I can discuss the object I have chosen (laughs). Erm, so the object I have chosen is my tablet. Erm, there are several reasons why I have chosen my tablet, it's because I love my tablet, it goes everywhere with me. But most explicitly, because of the work life balance nature of your research, because my tablet has enabled me to synchronise my work comp..my work diary with my diary that I share with my husband, which enables me to achieve the ridiculous list of things I'm supposed to achieve because…[inhale] I kept double booking myself so that because with the caring commitments and with my children, and work and study I couldn't keep my commitments in my head, and I kept muddling up and not turning up to stuff, and there's that synchronisation there that's enabled me to be where I'm supposed to be [Sustainability – synchronisation/organisation], and the fact that I can set reminders so that my phone beeps at me to say 'ok', like I had my appraisal with my Line manager yesterday, and I was able to tell him 'you have me for 35 minutes' and then my phone is beeping at me [whispers: which is ridiculous] but that's what I have to do, because there's just no time. I have no time, and and then, I was saying, in the bit that's a bit repeaty (from starting to discuss early on) that I noticed that when I was going through… when I was thinking about the object, the reason I was thinking about my mum's teddy bear, but that's my mum's memories, and that has nothing to do with my like, work life balance, and when I looked at my calendar, my mum is rarely on it, unless she has a hospital appointment or a doctors appointment but she is all the gaps in between everything else….she fills...sucks up...all those, the bits in between.
Researcher: Erm…and is there anything else about how the object represents your experience as a working family carer?
DWC1: Yyesss…erm, because it enables me...and this drives my husband mad, but it enables me to check my emails in bed. It [laughs] enables me to do my research work while stood waiting for a train to turn up. It facilitates me to do micro-tasks whilst on the move [laughs] which is just potty..so that I can make the most of every little bit of minute I've got to try and achieve what I need to achieve [Sustainability – organisation/micro-tasks].
Researcher: Why did you choose to be a working family carer?
DWC1: Let's unpick the notion of choice….the w..[laughs]..where is the choice? [laughs] [Challenges – lack of choice/burden of caregiving], I mean I w...we had these conversations when we chose to home school my little boy as well. That was not a CHOICE. The school could not meet his learning needs. And he was becoming damaged by the system so that wasn't a choice. It coincided with his diagnosis, and the choice we made was to put our family first, but that's not a choice is it? I mean y…we were pleased to know that we could home school him and care for mum at the same time, but we didn't choose any of those things, but mum was diagnosed with dementia, she, we couldn't really be leaving her on her own anymore. What um what would we do with her? I would you just choose to ignore that situation and leave her on her own all day? You you..does…that's...neglect [laughs]. So….yeah. I think choice is an odd term [Challenges – lack of choice/burden of caregiving].
Researcher: And anything else about how you manage to combine work and care?
DWC1: [long laugh]. Badly. Um….We always make sure someone's at home at any one time, you know. There's always somebody in the house, and the way we have been able to do that is because my husband reduced his work hours, so he used to work full time and now he works part time, and I work 0.8, so I'm not quite full time [Sustainability – flexibility at work/partner care caring (support at work and from partner)], so we've taken quite a financial hit [Challenges – care-work conflict (financial impact)] to enable us to make sure there's always somebody in the house, so that we can care for both child and…grown up child, and that's the only c…there's no, so, I mean that's the notion of choice isn't it. It, lots of people couldn't choose to do that and cover their mortgage or their rent or whatever. So, I suppose we did have a degree of choice there in that we were, well I was in a job that I was well paid enough, that I could go

right I can just about cover all our outgoings on our wages [Sustainability? – circumstantial regarding economic benefits]. So we did have that choice...and thank god we did cause I can imagine so many people don't…and then what do they do? I mean, I guess...their parents have falls or, aren't cared for or people…I don't know how people cope.
Researcher: And can you elaborate on those experiences which are successful in combining work and care?
DWC1: [Laughs]…We are all still alive [laughs]. Oh god that's sounds really facetious and I don't mean it to be! Erm…mum has...the main success has been mum's he outcome um you know, in that because she lives with us we got her diagnosis quite early which meant we got her onto the right drugs quite early, which then has slowed the rate of her decline...which has been really positive…because she is fed and watered regularly, because that's what we do um…that has meant her health has been kept steady, you know, whereas I think if she was on her own she wouldn't eat so well, she wouldn't remember to keep her fluids up. And I know when I come home from work sometimes I go 'eh-up, she needs a cup of tea cause I can see she's getting drawn…um, so we know to keep an eye on her fluids, which she wouldn't do...so that is a daily success I suppose, that we're keeping her as good as she can be, given everything else, for as long as possible. [Sustainability? – less of a strategy, more circumstantial].
Researcher: How could having a job help you as a carer?
DWC1: It means I don't have to be there 24 hours a day [laughs]…[Sustainability – work perceived as a break from providing care] cause as much as you love your mum, I could not do this full time. There is…I love my children…there's no way I could be a full-time mum. I love my mum, there is no way I could deal with her 24 hours a day. You just wh…you would love them. I don't, you know I wouldn't say you'd love them less, but I can't imagine the stress of doing that 24 hours a day [Sustainability – work as a respite from care stressors], and it is something we are aware of moving forward. And because we are on a one-way journey here aren't we, and we're always trying to think 'ok, what's coming next, and that is a big concern. Yeah.
Researcher: And how could being a carer help you at work in your job?
DWC1: I think…I'm more….I think with my students I have more sympathy more empathy for the kind of challenges some of them face [Sustainability – care-work benefits/empathy/transferable skills], you know that the whole university system around this idea that these free, young people with no commitments, and actually some of them are carers. Actually some of them work. Actually some of them are balancing quite difficult competing demands, and actually some of them have really bad self-esteem issues as a result. And, so I think having that kind of experience enables me to acknowledge that and share that experien [Sustainability – care-work benefits/empathy/transferable skills], you know, not that I'd ever talk about my, I have, I have used myself as a carer as an example when we've been talking of, ya know, when I teach them gender roles in the family and stuff like that, I will draw on myself as an example, erm, and I think it makes me a more supportive colleague because I don't think I expect perfection or a hundred percent professionalism (laughs)…[Sustainability - care-work benefits/empathy/transferable skills] perhaps because I find that hard to deliver, so I guess that's, yeah. I don't know if they're really good (unintelligible) my boss not say that's good, you know what I mean 'I don't know' (boss' voice), I don't know but I think it may mean you're more rounded. You know, we have to think that we are three dimensional beings, we're not just workers, we're people who work.
Researcher: And how does combining work and care fulfil you personally?
DWC1 [thinks]. I don't think it does….No, I don't think it does. This isn't what I wanted [laughs]. It sounds really childish, I you know, I do it, I don't, maybe I do resent doing it, I don't know, I don't think I resent doing it, but this isn't...what I wanted out of life, and when I look at my career my research would be going a lot better if I didn't have to do this, and I would be able to go to that symposium or that conference, or give that talk [Challenges – care-work conflict (professional impact)], or do all that stuff that gets you…that I can't...do [laughs].

Appendix XII:

An example of challenges and sustainability quotes organised by themes and sub-themes

DWC	Gender	Age	Job	Relationship	Artifact	Quote	Theme	Sub theme
1	F	47	Teaching fellow/PhD student	Daughter	Tablet	...where is the choice? [laughs]…[ ]...mum was diagnosed with dementia, she, we couldn't really be leaving her on her own anymore. What um what would we do with her?	Burden of caregiving	Duty
14	M	45	Manager and adult education tutor	Son	Keyring	...sometimes it is a reminder I think if you can work that there is, there is an outside world still cause caring can be very isolating and, and a very lonely experience, and you can sort of very trapped erm in an, in a small world with the person you're caring for...	Burden of caregiving	Isolation
6	F	47	Mental health trainer/consultant	Daughter	Rubiks cube	...I sort of thought of trying to do a Rubik's cube which I never mastered but I could always manage to do one side, and that's really what it feels like. I can do one of the things I have to do fine, but you can't…the other side's completely abandoned while you're concentrating on that side and as soon as you start on another side you mess up the first side.	Work-life conflict	Overlap – cognitive/functioning impact
9	M	79	Self-employed farmer, OPA (ospehagal patients association), therapist (Sports), construction	Spouse	Car	…one of my complaints to myself, is that er…I'm no longer able to...I used to go swimming regularly. I can't do that now...[ ]...Erm…I used to go on much longer walks, much more regularly, which I now don't do because I haven't got the time to do it, so it's a time related thing. I don't…because I've re-ordered my priorities, those are the things which I've actually put at the bottom of the list, so they	Work-life conflict	Overlap - time constraints

			adviser			don't get done.		
24	F	40	Clinical support worker	Daughter	Reading App	...I don't have any time. I don't have enough time to do anything. I don't have any support...so trying to juggle that, and the competing needs of like, mum and my daughter and my job, erm...and studying as well cause I'm doing my erm, nurse training, so that on top, like…yeah, there just wasn't any respite at all…	Work-life conflict	Overlap - triple-duty caregiving
21	F	62	Foster carer	Daughter	Potato peeler	I think that the feeling of constantly juggling people who all need my attention at once. Erm…making sure that everybody gets the attention that they need. Erm…getting tired. I think that's…it's a strain at times.	Work-life conflict	Overlap - Wellbeing impact tiredness/mental
16	F	54	Occupational therapist	Daughter	Yoga mat/Swimming costume	I have a full on, full time stressful job, and the sort of emotional stress I guess of thinking about supporting my dad, and so I, what I try to do is before and after work or at least one or the other, either go for a swim in the sea, which is my absolute joy and passion […] Or I practice yoga, or I just sit on my yoga mat and meditate or chill out […] I just love being in the water, of being supported by the water, of just thinking 'I don't care what else happens today, I've got in the sea' […] that's [yoga] more grounding […] both times, I haven't got my phone […] I'm uninterrupted, that's my time.	Relaxation/ Respite	Physical exercise
19	F	61	General Duty Manager - Bookshop (main role)	Daughter	CD	Well balancing work and care and me time, cause there's three angles on it, and quite a lot of the downtime from the caring at the moment is devoted to the work. So I have to try and make sure that I get something that isn't that. So I guess […] this is the 'me'	Relaxation/ Respite	Time alone (mental)

						time.’		
2	M	40	Business analyst	Son-in-law	Fountain pen	My works policy is generally very good. So, they’ve allowed me to do both flexibly. Provided me with a laptop to work from home, provided whatever support they can there. There’s an employee assistance programme where you can phone up for counselling. They do regular mental health at work days to make sure everyone’s okay	Support	Workplace
11	M	66	Dementia support group co-ordinator	Spouse	iPad	The examples that I see from our friends and the …I guess that the, the support that we give each other…is important to me, yeah, yeah, yeah.	Support	Friends/family (home)

Appendix XIII:

An example of challenges and sustainability refined themes and sub themes

Challenges	
Participant	Quote
Caregiving burden	
Isolation	
DWC3, spouse, age 62, Cleaner.	...the caring thing [magazine], is a bit sort of sad really. l think caring for someone can be sad, when they are being sad and you can't make them happy
DWC6, daughter, age 47, Mental health trainer/consultant	...isolating as well, because nobody really understands it…
DWC14, son, age 45, Manager and adult education tutor.	...sometimes it is a reminder I think if you can work that…[ ]…there is an outside world still 'cause caring can be very isolating and, and a very lonely experience, and you can sort of very trapped…[ ]…in a small world with the person you're caring for...
Duty of care	
DWC24, daughter, age 40, Clinical Support Worker	It got thrust upon me, I didn't choose it at all [laughs]...[ ]...I'm just the only relative, so it falls to me.
Work and life conflict	
Work and life conflict (Everyday functioning impact)	
DWC6, daughter, age 47, Mental health trainer/consultant	...I sort of thought of trying to do a Rubik's cube which I never mastered but I could always manage to do one side, and that's really what it feels like. I can do one of the things I have to do fine, but you can't…the other side's completely abandoned while you're concentrating on that side and as soon as you start on another side you mess up the first side.
DWC13, spouse, age 79, Lifeguard trainer	...my life is muddled.
DWC12, son, age 58, Bus driver	…everything is a bit of a balancing act really…you know on one side you've got your family and on the other side you've got the person you're caring for.
DWC17, daughter, age 55, Teaching	...sadly work and caring has a very negative effect on my attention span. Erm, you know, my short-term memory, although it wasn't brilliant before all of this, I find that I have to just write reminders down to myself, erm you know, and I have to really plan my lessons even more

	carefully…[ ]… it eases a huge amount of energy er, because I start to forget things more easily now because of both roles.
Work and life conflict (Time constraints)	
DWC9, spouse, age 79, Multiple working roles (Self-employed farmer - main)	...one of my complaints to myself, is that…[ ]…I used to go swimming regularly. I can't do that now...[ ]…I used to go on much longer walks, much more regularly, which I now don't do because I haven't got the time to do it. So it's a time related thing.
Work and life conflict (Triple-duty caregiving)	
DWC24, daughter, age 40, Clinical Support Worker	...I don't have any time. I don't have enough time to do anything. I don't have any support...so trying to juggle that, and the competing needs of like, mum and my daughter and my job …and studying as well cause I'm doing my nurse training, so that on top, like…yeah, there just wasn't any respite at all…
Work and life conflict (Mental impact)	
DWC24, daughter, age 40, Clinical Support Worker	It just makes me feel very depressed really, because I think, because I don't have a life, and so I feel really old before my time.
Work and life conflict (Physical impact)	
DWC21, daughter, age 62, Foster carer.	I think that the feeling of constantly juggling people who all need my attention at once…making sure that everybody gets the attention that they need…getting tired…[ ]…..it's a strain at times.
Work and life conflict (Social impact)	
DWC3, spouse, age 63, Cleaner	I suppose I don't go out some much really, more of an effort to go out.
Life-work conflict (Economic/professional wellbeing)	
DWC1, daughter, age 47, Teaching fellow/PhD Student	...this isn't…what I wanted out of life, and when I look at my career my research would be going a lot better if I didn't have to do this. And I would be able to go to that symposium or that conference, or give that talk, or do all that stuff that gets you…that I can't…do [laughs].
DWC12, son, age 58, Bus driver	Er, but it has meant an enormous er change and sacrifice on my part…[ ]… ...I've actually given up my thriving career of 30 years…[ ]… I've given up [laughs] a sort of my pension with my previous employer, and I've given up a…[ ]…substantial salary in order to sort of downsize and try and find a balance, and that balance has resulted in me doing a less demanding job. A completely different career change and a vast reduction in…[ ]…income to the family budget.
DWC20, son, age 54, Business owner	...when you've got a business, you know, the money's never gonna be equal week to week to week to week, and it should be something that's you know if it, you know, and also then there's the expenses so you know, quite often when you've taken away all the things you've had to pay for and everything else, there's maybe not much profit that's actually being earned or, or you might even wanna have some of that money stay within the business, so it's you know, you might be able to say 'well I might pay myself a wage, maybe that's only the amount that they're gonna let me have, but then what do I do with the excess? Can I actually then put that..?' A lot of these questions aren't answered by the government

	Sustainability
Participant	Quote
	Respite strategies
Physical methods	
DWC16, daughter, age 54, Occupational therapist	I have a full on, full time stressful job, and the sort of emotional stress I guess of thinking about supporting my dad, and so I, what I try to do is before and after work or at least one or the other, either go for a swim in the sea, which is my absolute joy and passion […] Or I practice yoga, or I just sit on my yoga mat and meditate or chill out […] I just love being in the water, of being supported by the water, of just thinking 'I don't care what else happens today, I've got in the sea' […] that's [yoga] more grounding […] both times, I haven't got my phone […] I'm uninterrupted, that's my time.
Mental methods	
DWC19, daughter age 61, General Duty Manager - Bookshop (main role)	Well balancing work and care and me time, cause there's three angles on it, and quite a lot of the downtime from the caring at the moment is devoted to the work. So I have to try and make sure that I get something that isn't that. So I guess […] this is the 'me' time.'
Support from home and work	
Workplace support	
DWC2, son-in-law, age 40, Business analyst	My works policy is generally very good. So, they've allowed me to do both flexibly. Provided me with a laptop to work from home, provided whatever support they can there. There's an employee assistance programme where you can phone up for counselling. They do regular mental health at work days to make sure everyone's okay
DWC11, spouse, age 66, Dementia support group co-ordinator	The examples that I see from our friends and the …I guess that the, the support that we give each other…is important to me, yeah, yeah, yeah.
Support at home	

Appendix XIV:

NHS Health Research Authority approval

NHS
Health Research Authority

Miss Rachel Clarke
PhD Student
University of Sussex
Essex House
Falmer
Brighton
BN1 9QH

Email: hra.approval@nhs.net

27 October 2016

Dear Miss Clarke

Letter of HRA Approval

Study title:	**Living well with dementia: Sustaining psychological wellbeing in working family carers**
IRAS project ID:	**203695**
REC reference:	**16/EM/0383**
Sponsor	**Sussex Partnership NHS Foundation Trust**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities

Confirmation of capacity and capability - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

A – List of documents reviewed during HRA assessment
B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

Registration of research
Notifying amendments
Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **203695**. Please quote this on all correspondence.

Yours sincerely

Miss Lauren Allen
Assessor

Email: hra.approval@nhs.net

Copy to: *Miss Taffy Bakasa, Sussex Partnership NHS Foundation Trust (Sponsor contact and Lead NHS R&D contact).*

NIHR CRN Portfolio Applications Team

Appendix XV:

Research Governance approval

Sussex Partnership NHS
NHS Foundation Trust

Research and Development
Sussex Education Centre
Mill View Hospital
Nevill Avenue
Hove BN3 7HZ

Tel: 01273 265928
Fax: 01273 242182

www.sussexpartnership.nhs.uk

24 November 2016

Miss Rachel Clarke
PhD Student
University of Sussex
Essex House
Falmer
Brighton
BN1 9QH

Dear Miss Clarke

Study Title: Sustaining psychological wellbeing in working family carers
Trust Ref: 203695

Thank you for your application to Sussex Partnership Trust to conduct the above named study with in the Trust. I am pleased to inform you that Sussex Partnership has the capacity and capability to conduct this study at the following sites:

- SPFT Dementia Services

Our confirmation of capacity and capability to host this research study relates to the specific protocol and informed consent procedures described in your HRA application form approved by the HRA, and by the Statement of Activities agreed with SPFT. Any deviation from this will be deemed to invalidate this confirmation.

The documents reviewed for this approval were:

Document	Version	Date
Letters of invitation to participant [Invitation letter]	1	24 March 2016
PPI feedback		08 April 2016
PPI responses		27 May 2016
Contact details form	1	21 March 2016
Follow-up letter	1	25 April 2016
Supportive services	1	23 September 2016

Sussex Partnership NHS
NHS Foundation Trust

Participant consent form	4	25 October 2016
Participant consent form [Photography]	3	25 October 2016
Participant information sheet (PIS) [Second visit]	4	26 October 2016
Participant information sheet (PIS)	4	25 October 2016
Participant information sheet (PIS) [Summary]	4	25 October 2016
Study Protocol	2	30 May 2016
Flowchart of Study Protocol	1	31 May 2016
Face to face questionnaires	2	28 April 2016

Conditions of Approval

CI: As Chief Investigator of the study you agree to fully comply with the Department of Health Research Governance Framework, in particular that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality.

Recruitment: As the project has been adopted by the NIHR, you are responsible for ensuring accrual numbers are submitted to the co-ordinating centre for study on a monthly basis. If you need any support to manage this please contact me.

Conflict of Interest: You are responsible for insuring that any conflict of interest by any member of the research team will be disclosed. This includes any arising during the course of the research.

Honorary contracts: Members of the research team must have appropriate substantive or honorary contracts or letters of access (as appropriate) with the Trust prior to conducting any research on Trust premises. Any additional researchers who join the study at a later stage must also hold a suitable contract or must contact the R&D department to arrange an honorary contract/letter of access prior to commencing work on this research study.

Essential Documents: A project file or site file will be maintained for this study. Support from the R&D Office can be sought in creating and maintaining a site file.

Amendments: Project amendment details dated after the issue of this approval letter should be emailed to the Research and Development Office (research.governance@sussexpartnership.nhs.uk). Trust confirmation of capacity and capability must be issued prior to the implementation of any amendment.

Sussex Partnership NHS
NHS Foundation Trust

Adverse Events: All adverse events and safety incidents will be reported to the study Sponsor as defined by the study protocol. In addition in line with SPFT Research Policy, you must report any adverse events and incidents to the R&D Office.

Monitoring: The Trust has a duty to ensure that all research is conducted in accordance with the Research Governance Framework and to ICH-GCP standards. In order to ensure compliance the Sponsor, Trust or Regulatory Body may undertake random audits and inspections. If your project is selected for a Trust inspection you will be given 4 weeks' notice to prepare all documentation for inspection. The trust undertakes annual monitoring of all research studies, please respond to any requests for information. Failure to do this may result in the Trust withdrawing its confirmation of capacity and capability. The information contained in this application, any supporting documentation and all correspondence with the R&D office may be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

Dissemination: Upon completion of the research the study team will be contacted to confirm arrangements for dissemination. Dissemination of findings is a condition of approval and will be monitored by the Research & Development Office. Failure to disseminate may result in the Trust being unable to support future studies.

I wish you luck with your project and would be grateful if you could inform me when the project is complete or due to be closed on this site.

Please sign below and return a copy to researchgovernance@sussexpartnership.nhs.uk

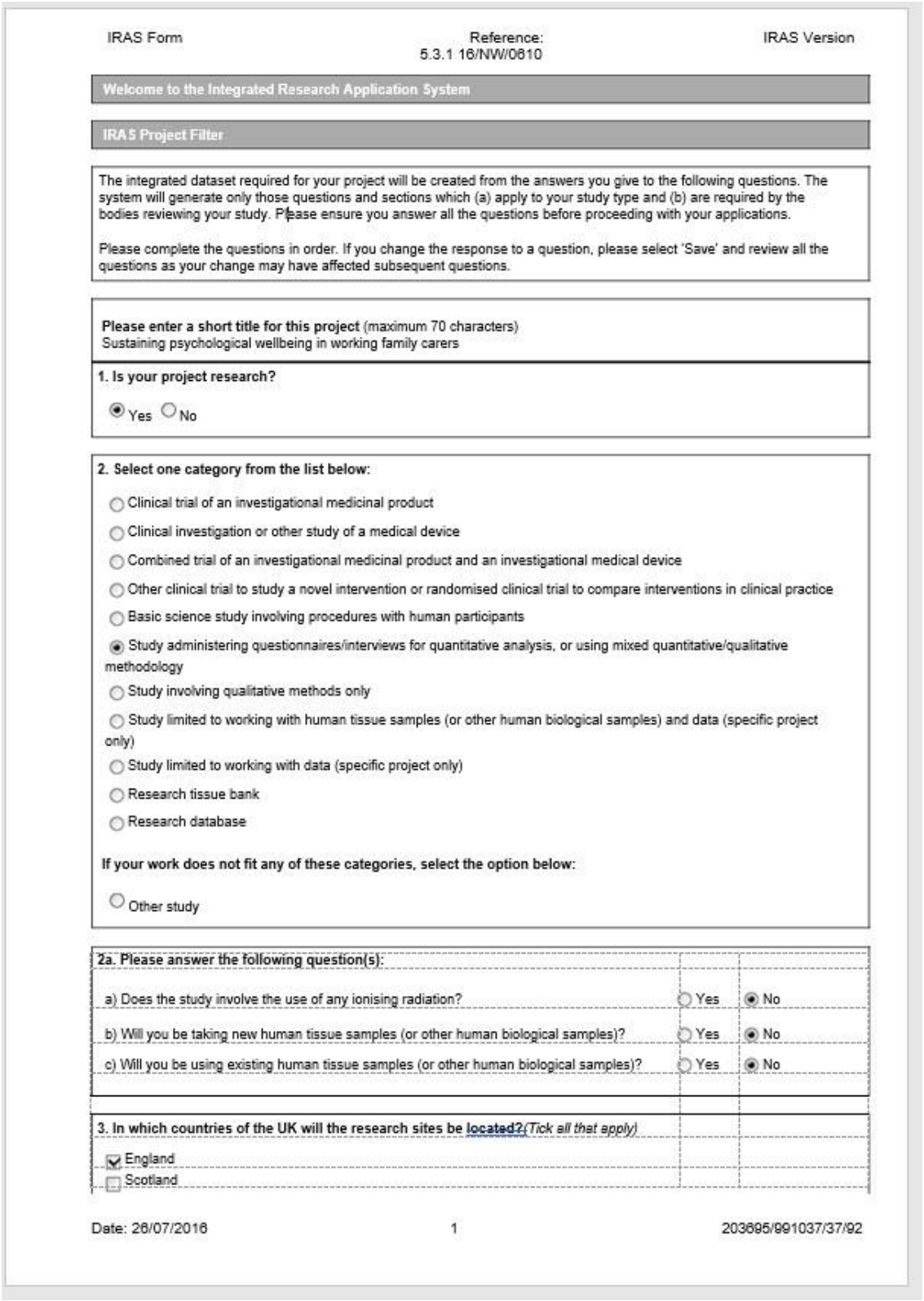
Yours sincerely,

Taffy Bakasa
Lead Research Governance Officer

Please sign and date this letter and return one copy. Do not detach this lower section from the letter.

Appendix XVI:

Thesis IRAS application



IRAS Form | Reference: 5.3.1 16/NW/0610 | IRAS Version

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Sustaining psychological wellbeing in working family carers

1. Is your project research?

(•) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
(•) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
( ) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):		
a) Does the study involve the use of any ionising radiation?	( ) Yes	(•) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(•) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(•) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[x] England
[ ] Scotland

Date: 26/07/2016 | 1 | 203695/991037/37/92

☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

◉ England
○ Scotland
○ Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

IRAS Form
Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

Yes No

5. Will any research sites in this study be NHS organisations?

Yes No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

Yes No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and Inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

Yes No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
This project is being undertaken as part of a PhD. The Chief Investigator will be responsible for the collection of quantitative and qualitative data and writing up the thesis.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Sustaining psychological wellbeing in working family carers

Please complete these details after you have booked the REC application for review.

REC Name:
North West - GM West

REC Reference Number:	Submission date:
16/NW/0610	26/07/2016

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Living well with dementia: Sustaining psychological wellbeing in working family carers

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title Forename/Initials	Surname
	Miss Rachel	Clarke
Address	Flat 5, Larkswood	
	Nyton Road	
	West Sussex	
Post Code	PO20 3UA	
E-mail	rachelclarke3@msn.com	
Telephone	07902651500	
Fax		

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

PhD - Social Work and Social Care

Name of educational establishment:
University of Sussex

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Lisa Henglien	Chen
Address	Department of Social Work and Social Care		
	Room EH213, Essex House		
	University of Sussex, Falmer, Brighton		
Post Code	BN1 9QN		
E-mail	h.l.chen@sussex.ac.uk		
Telephone	01273873721		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Professor	Jennifer	Rusted
Address	Department of Psychology		
	Pevensey 1 2B21, University of Sussex,		
	Falmer, Brighton		
Post Code	BN1 9QH		
E-mail	j.rusted@sussex.ac.uk		
Telephone	01273678325		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Rachel Clarke	☑ Dr Lisa Henglien Chen
	☑ Professor Jennifer Rusted

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (●) Student
- ( ) Academic supervisor
- Other

A3-1. Chief Investigator:

IRAS Form		Reference: 16/NW/0610	IRAS Version 5.3.1
	Title Forename/Initials	Surname	
	Miss Rachel	Clarke	
Post	PhD Student		
Qualifications	MSc Mental Health Studies BSc (hons) Psychology		
Employer	University of Sussex		
Work Address	Essex House		
	Falmer		
	Brighton		
Post Code	BN1 9QH		
Work E-mail	rc362@sussex.ac.uk		
* Personal E-mail	rachelclarke3@msn.com		
Work Telephone	07902651500		

* Personal Telephone/Mobile 07902651500

Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project? *This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

	Title Forename/Initials	Surname
	Miss Taffy	Bakasa
Address	Lead Research Governance Officer	
	Sussex Partnership NHS Foundation Trust	
	Millview Hospital, Nevill Avenue	
Post Code	BN3 7HY	
E-mail	taffy.bakasa@sussexpartnership.nhs.uk	
Telephone	01273265909	
Fax		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number: ES/I001853/1

Project website:

Additional reference number(s):

Ref Number	Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)"

section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.
This project is linked to the Living well and enhancing active life: the IDEAL study, Ref: ES/I001853/1. This PhD is directly funded from the IDEAL study grant award.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

This study is focusing on working family carers of a person with dementia. Enabling family carers to live well with dementia is a key UK policy objective. Whereas research efforts with regard to family carers who care for people with dementia typically seek to understand their caring experience, their relationship with the person with dementia, and the effectiveness of support interventions, this study proposes to focus on sustaining psychological health and quality of life for working family carers – family carers who remain in employment. The abolition of the default retirement age means that there are likely to be increasing numbers of family carers who face the challenge of sustained care and work. Although little is known about the profile of the increasing numbers of family carers for people with dementia who are combining work and care, or withdrawing from the workforce to provide care. This study will address this knowledge gap firstly, by asking approximately 30-50 working family carers of a person with dementia to provide information about areas which contribute to their: psychological wellbeing, their everyday functioning (i.e. basic memory and attention), and their work and life balance. This will yield numerical data that will be analysed statistically. Following this, in-depth interviews will be conducted with all working family carers to enrich the knowledge gained from quantitative analyses and further understand the factors which support a sustainable work and life balance. These findings will be complemented by a comparison of the factors associated with psychological wellbeing between a larger cohort of working and non-working family carers from the national 'Living Well with Dementia' project. In the final stage, all results will be merged to develop a model of sustainable work and life balance which assists in the development of services and support for working family carers in the UK.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

We think that the main ethical issues are informed consent, confidentiality, participant vulnerability, security of data, and researcher safety.

Informed consent:
1. Provision of information. Information about the study will be provided beforehand and clarified here necessary by the researcher when meeting face-to-face (See Participant Information Sheet). Information about the study will be clear and easy to understand so that participants can make an informed choice about taking part.
2. Indication of voluntary nature. The information will indicate that the participant can withdraw at any time from the study, and request that their data is withdrawn and destroyed.

Confidentiality. Procedures will be in place to ensure that participants cannot be personally identified from any data sources and that the information they provide remains confidential, except in unique cases where this needs to be overridden by concerns about mental and/or physical wellbeing. Only then will details be shared with a designated

professional as part of the protection for vulnerable adults.

Participant vulnerability. In order to protect the welfare of participants, interviews can be paused or stopped completely if participants communicate that they feel uncomfortable. The Chief Investigator will also look for non-verbal cues which signify discomfort. Additionally, participants will be made aware that they do not have to answer questions they would prefer not to.

Interviews will be delivered in a sensitive manner and the requirements of each section will be explained beforehand, and close with a series of positive questions (see Example of questionnaires).

Security of data. In accordance with the Data Protection Act (1998) and the British Psychological Society Code of Ethics and Conduct (2009), the analysis of data will take place in a secure office on the premises of the University of Sussex. Access to personal data will be protected by password and stored separately from other data collected during fieldwork. When data is collected off premises, it will be collected on a password protected/encrypted device.

The transfer of secondary data from the linked Living Well with Dementia study has already been approved by an ethics committee (see IDEAL IRAS application) and by participants for scholarly and educational purposes (see IDEAL Consent form).

Researcher safety. Prior to fieldwork, supervisors will be informed of the location and the expected time of arrival and departure by the Chief Investigator. A text will be sent to the supervisors within an hour of the anticipated time of arrival and departure from locations. If a text is not received, the supervisors will follow up with a telephone call. To ensure the safety of the Chief Investigator is not compromised, fieldwork will not be conducted when both supervisors are out of the country.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☑ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

This study aims to extend our understanding of factors associated with sustainable psychological wellbeing in family carers of a person with dementia who are maintaining employment alongside the caring role. The research questions are as follows:

1. What factors are associated with sustainable psychological wellbeing, everyday functioning and work and life balance among working family carers of a person with dementia?
2. How do working family carers contextualise the experience of sustainable work and life balance?
3. Do working and non-working family carers of a person with dementia differ in measures of psychological wellbeing?

4. What is the relationship between sustainable psychological wellbeing, everyday functioning and work and life balance?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

The secondary research questions is:
Can we identify a quantitative measure of performance change that correlates with qualitative measures, by looking at measures of attention and distraction?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Developing service support for family carers of people with dementia to meet their changing needs is a key UK policy objective. Exploring the factors associated with sustainable psychological wellbeing among working family carers occurs in line with the recent abolition of the default retirement age. As more carers extend their working life, the number of family carers who face the challenge of sustained care and work is likely to increase. Furthermore, local authorities are expected to meet the wellbeing needs of those working family carers, according to the latest Care Act (2014). Older (non-working) adult family carers of a person with dementia, frequently report high levels of depression and physical illness, and a poor quality of life. Although, the delay in retirement age creates a greater challenge for working family carers who are maintaining multiple roles which are shown to have both negative and positive effects. Very little research has been conducted into the increasing numbers of family carers of a person with dementia who are continuing to work past the default retirement age and provide care. It can be argued that there is a significant knowledge gap to support family carers living well with dementia while responding to the least national expectation on their care and work roles. Therefore, as the support of family carers of people with dementia is a significant policy objective in the United Kingdom, this study will address this knowledge gap by conducting addressing the needs of family carers who are rarely involved in research studies. The outcomes of this research will provide a deeper insight into how family carers of a person with dementia balance work and care, and what areas of work and life balance remain unsupported. These findings will be fed back to research and policy to assist in the development of services for working family carers of a person with dementia.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Recruitment:

Potential participants who satisfy the inclusion and exclusion criteria (see A17-1 and A17-2) and live in areas based around East and West Sussex, will be recruited by the Chief Investigator with support from a Research Nurse at Sussex Partnership Trust who will help facilitate the use the databases and access to clinical teams. Sussex Partnership Trust have agreed to assist with recruitment for this project, which was reviewed by the SPT Dementia Research Board, at their meeting on 18th May 2016. Recruitment will be based on self-referrals from voluntary services, Sussex Partnership databases of people who have expressed interest in taking part in research (e.g. Join dementia research (JDR)), referrals from Sussex Partnership dementia services or from other ongoing trials such as MODEM (modelling outcome and cost impacts of interventions for dementia). If potential participants meet the criteria necessary to participate in the study, they will be sent an invitation letter, a Participant Information Sheet, an Informed Consent Form, a Photography Consent Form, a Contact details form and a stamped addressed envelope for the return of contact details forms and consent forms to the Chief Investigator. Once signed consent forms have been received, the Chief Investigator will contact participants to arrange the first visit.

Stage 1 – Questionnaire and Quantitative data collection:

All visits will be conducted in the participant's home or in another location of their choice. The first visit will involve the administering questionnaires face-to-face.

1. Questionnaires and cognitive test;

The questionnaires will measure the factors associated with: psychological wellbeing; everyday functioning, and work and life balance. The study will begin by asking some demographic questions to explore the background context of the participant, including: occupation; income bracket and number of hours spent caring and working. There will also be a 5-minute computerised card sorting task (Farina et al., 2013) to assess decision making ability as an objective assessment of the participant's everyday functioning. This test will be conducted on the Chief Investigator's personal password protected computer. Output from the task will be identified only by participant ID number and will contain no identifiable information. This task uses the same paradigm with older people and people with dementia, thereby

demonstrating that it has been appropriately piloted. This stage of the study is expected to last from 1.5 to 2 hours and will be conducted across 2 visits, unless participants prefer to complete the questions in one visit.

At the end of stage 1, participants will receive a verbal explanation of what will happen during stage 2. Explanation will involve a briefing about the areas of focus for the interview and to select an item of personal significance which represents the work and life balance. Interviews will take place around two weeks following the completion of stage 1 and they will be provided with an information sheet (see Information Sheet for second visit).

One week before stage 2, the Chief Investigator will send participants a follow up letter by email or post to thank them for their participation (see Follow-up letter) and remind them about the date and time of the arranged visit. A Participant Information Sheet summary (attached) and consent forms will also be re-sent to ensure participants are still happy to continue.

Stage 2 - Qualitative data collection:

2. Semi-structured interviews;

For stage 2, semi-structured interviews will begin by asking participants to discuss the item they have chosen to represent the work and life balance. Participants will be encouraged to discuss their object freely and where necessary, will be given prompts. The prompts to questions are open as topics to be discussed. In addition, time will also be given to the participants to raise any issues they thought important to this topic that have not been brought up by the Chief Investigator. This stage of the study is expected to last from 1.5 to 2 hours.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [ ] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [ ] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
A meeting was arranged with both supervisors, the Chief Investigator and a PPI Dementia Consultation group at Sussex Partnership Trust on 6th April 2016, to review the study design and accompanying paperwork. This group is made up of service users with dementia, carers of a person with dementia and a coordinator for service user and carer involvement. The group provided guidance (see PPI feedback and PPI responses) which resulted in modifications to the study. The PPI group will also be consulted for ideas in regards to dissemination of findings.

The group will also be invited to be involved in dissemination of the findings.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- [ ] Blood
- [ ] Cancer
- [ ] Cardiovascular
- [ ] Congenital Disorders
- [ ] Dementias and Neurodegenerative Diseases

- [ ] Diabetes
- [ ] Ear
- [ ] Eye
- [x] Generic Health Relevance
- [ ] Infection
- [ ] Inflammatory and Immune System
- [ ] Injuries and Accidents
- [x] Mental Health
- [ ] Metabolic and Endocrine
- [ ] Musculoskeletal
- [ ] Neurological
- [ ] Oral and Gastrointestinal
- [ ] Paediatrics
- [ ] Renal and Urogenital
- [ ] Reproductive Health and Childbirth
- [ ] Respiratory
- [ ] Skin
- [ ] Stroke

Gender:	Male and female participants
Lower age limit:	Years
Upper age limit:	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Working family carers of a person with dementia who are working on a voluntary or paid basis for a minimum of 10 hours and providing at least 10 hours of care per week as per the guidelines used in previous studies with working family carers (Hoff et al., 2014);

Working family carers with a minimum of 1 year in the care role;

Working family carers who live with the person with dementia. This is based on research which has found that caregiver burden is more likely to occur among family carers who live with the person with dementia and family carers who have decided to institutionalise a person with dementia (Spitznagel et al., 2006).

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Working family carers who provide care for an individual with Frontotemporal dementia (FTD). FTD is the only early onset dementia and therefore could introduce potential confounds into the study, including greater rates of carer depression and dementia related behavioural challenges (Nicolaou et al., 2010).

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research,

how many of the total would be routine?

3. Average time taken per intervention/procedure (minutes, hours or days)

4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
A Research Nurse will contact potential participants to check they meet the inclusion and exclusion criteria (see A17-1 and A17-2).	1	n/a	15 minutes	Research Nurse - Sussex Partnership Trust
Invitation letters, the Participant Information Sheet, Consent Forms, the Contact details form and stamped addressed envelopes will be posted to potential participants and returned to the CI	1	n/a	15 minutes	Research Nurse - Sussex Partnership Trust
The Chief Investigator will telephone or email potential participants who have returned consent forms to arrange an appointment for the first visit.	1	n/a	5 minutes	The Chief Investigator from Sussex University premises
First visit - administering questionnaires and the computerised card sorting task	1-2	n/a	90 - 120 minutes	The Chief Investigator - in participants' home or other location chosen by the participant
Sending follow-up letters, Participant Information Sheet Summary, Consent forms and stamped addressed envelopes to participants before visit 2 (or 3 if visit 1 requires 2 visits)	1	n/a	10 minutes	The Chief Investigator from Sussex University premises
Second (or third) visit - Conducting semi-structured interviews	1	n/a	90 - 120 minutes	The Chief Investigator - in participants' home or other location chosen by the participant

A21. How long do you expect each participant to be in the study in total?

Participants are expected to be in the study for a maximum of 4 hours with 2 - 3 weeks between the first and second stage of the study. The total duration of participant involvement in the study is around 8 - 10 months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

1. Risks - The potential risks to participants have been identified with a Dementia Consultation group. Participants will be advised prior to taking part in the study that there is some risk of emotional distress and that I have a responsibility in line with good research practice to inform a designated professional, if there are significant concerns for their wellbeing. To reduce emotional distress, participants will be informed that they do not have to answer any questions they do not want to and that sessions can be paused or stopped completely. Questionnaires will also end on a positive note by asking questions pertaining to the positive aspects of being a carer. Instructions provided at the beginning of each questionnaire will be delivered in a way to soften the questions which follow. Attention will also be made to non-verbal cues given during interviews which may signify discomfort. If discomfort is suspected, the Chief Investigator will ask the participant if they are still happy to continue or would like a break.

2. Burdens - As each stage of the study lasts a maximum of 2 hours and the time of working family carers is already limited, I will be prepared to arrange a follow-up visit if there is an issue or a limitation with the participant's availability for long periods. Each stage of the study will also be conducted in an environment which is convenient for the participant.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

In instances where the questionnaires or interviews may cause emotional distress, all participants will be informed that the questionnaires or interview can be paused or completely stopped and rearranged for a follow up visit. Questions asked during interviews will also be softened in a brief introduction before each instrument which explains what I am going to ask, why and if they have ever felt this way. Participants will also be advised that they do not have to answer any questions they would prefer not to.

In the interests of safeguarding vulnerable adults, participants will be informed that if views are expressed which indicate a significant risk to their wellbeing, a designated professional will contact them to talk to them about it.

A24. What is the potential for benefit to research participants?

Participants may find that the opportunity to reflect on their experiences of work and life balance is rewarding in itself. The interview is also designed to explore the experiences of the participants in an open way. This may prove to be cathartic to participants, who otherwise may have little opportunity to discuss their own views of the benefits and challenges of combining care and work.

A26. What are the potential risks for the researchers themselves? *(if any)*

The potential risks to the researcher involve fieldwork which increases the risks associated with lone travel to unfamiliar locations. In this instance, the study supervisors will be informed of the location and the expected time of arrival and departure. A text will be sent to the supervisors within an hour of the anticipated time of arrival and departure from the location. If a text is not received, the supervisors will follow up with a telephone call. In cases where fieldwork takes place outside of office hours, access to supervisors will apply in the same way as it does within office hours. Fieldwork will not take place when both supervisors are out of the country.

As the nature of the fieldwork includes asking participants sensitive questions for extended periods of time, there is also a risk to the wellbeing of the researcher. To reduce the risk of harm, there will be regular supervision with both supervisors to monitor the progress of fieldwork and to address any concerns/questions. Professional emotional support can also be sought on campus premises via the Student Life Centre.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Potential participants will be identified with the support of a Research Nurse at Sussex Partnership Trust according to the inclusion and exclusion criteria of the study (see A17-1 and A17-2). This Research Nurse will help facilitate the use the databases and access to clinical teams. Potential participants will be recruited via self-referrals from voluntary service, referrals from Sussex Partnership dementia services, from Sussex Partnership databases of people who have expressed an interest in taking part in research (e.g. the Join dementia research database) or by other ongoing trials such as MODEM (modelling outcomes and cost impacts for interventions for dementia).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:
Potential participants' personal information will be identified by a Research Nurse. For the purposes of this study, family carers would have already provided their contact details and agreed to be contacted for research purposes.

A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. *Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected. Please consult the guidance notes on this topic.*

Research Nurses at Sussex Partnership Trust are compliant in data protection and confidentiality regulations. The Research Nurse will have had permission to access the personal details of potential participants who have registered interest in research projects.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Participants will first be approached directly, by telephone call or letter by a Research Nurse at Sussex Partnership Trust.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

The Informed Consent Form and Photography Consent Form will be posted along with a Participant Information Sheet by the Research Nurse, to ensure that participants are fully informed about the study. The Informed Consent Form highlights that the participant can withdraw at any time and without giving a reason, and that their identity and responses will be anonymised in published material.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Once information has been sent to participants, their decision whether to participate will be at their discretion and will not be followed up. If participants do not return consent forms within six weeks from the posting date, it will be assumed that they are not interested in participating in the study and other potential participants will be contacted. This method is considered the most appropriate as participants are able to make a decision via informed choice.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

For participants who are not proficient in the English language or who have communication needs, efforts will be made to translate questionnaires and additional documents into the participant's preferred language, and a relevant expert will be recruited (with permission) to accompany the Chief Investigator on visits.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- (●) The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ( ) The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ( ) The participant would continue to be included in the study.
- ( ) Not applicable – informed consent will not be sought from any participants in this research.
- ( ) Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Working family carers are assumed to have capacity to consent for themselves. Any issues with capacity affecting participation in research can also be assessed directly by the Chief Investigator during fieldwork. If it is apparent during fieldwork that the participant has lost capacity to continue with the study, they will be withdrawn from the study in addition to any data that has been collected. As the participants' contribution to the study is reliant on both stages of the project, it would not be beneficial to the study or to the integrity of the participant themselves, to retain their data.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- [ ] Access to medical records by those outside the direct healthcare team
- [ ] Access to social care records by those outside the direct social care team
- [x] Electronic transfer by magnetic or optical media, email or computer networks
- [ ] Sharing of personal data with other organisations
- [ ] Export of personal data outside the EEA
- [x] Use of personal addresses, postcodes, faxes, emails or telephone numbers
- [x] Publication of direct quotations from respondents
- [ ] Publication of data that might allow identification of individuals
- [x] Use of audio/visual recording devices
- [x] Storage of personal data on any of the following:
  - [x] Manual files (includes paper or film)
  - [ ] NHS computers

- ☐ Social Care Service computers
- ☐ Home or other personal computers
- ☑ University computers
- ☐ Private company computers
- ☑ Laptop computers

Further details:
Personal data and data generated by the study will be stored on a password protected university database and physical copies will be stored in locked filing cabinets. Personal contact details (i.e. addresses) will only be used to post participants information about stage 2 follow-up visits. Interviews will be recorded using a password encrypted dictaphone and direct quotes from participants will be edited to ensure the anonymity of participants is maintained. Photographs of objects selected for discussion during interviews will be taken by a password protected tablet, and the computer memory task will be performed on a password protected private laptop. Any data which has been collected via portable media will be transferred to a password protected university database and permanently deleted from the device. The Chief Investigator and the CI's supervisors are the only persons who will be granted access to data on the dictaphone, tablet and private laptop.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Physical data i.e. completed questionnaires, contact details forms and consent forms will be stored in separate lockable filing cabinets to avoid linkage of personal information to data generated by the study. All offices in the university are locked when not in use.

Data will which has been collected by dictaphone, tablet and laptop computer will also be identified only by ID numbers, and stored on a password protected database on university premises. The Chief investigator will only be able to access this data initially with shared access with the first supervisor and second supervisor.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All data will be anonymised. Each participant will be assigned an identification number which will be used on all documents, data files and transcripts. The document which links participant ID numbers to participant names will be stored on the University of Sussex password protected database. The NHS Code of Confidentiality (2003) will be followed by the Research Nurse at Sussex Partnership Trust to ensure the security of personal information of potential participants is maintained. The data protection act (1998) and BPS Code of Ethics and Conduct (2009) will also be adhered to by the research team at Sussex University while participants are involved with the study.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The personal data of participants will initially be accessed by a Research Nurse at Sussex Partnership Trust. Participants will themselves have provided these details, and will return contact details forms to the Chief Investigator at the University of Sussex. Hence, consent to personal data is implied. Personal data and data collected during fieldwork will be shared only with the Chief Investigator and both supervisors of the study. Participants will be made aware that any data published will not lead to their identification.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data will be analysed by the Chief Investigator under supervision by her supervisors. Data analysis will take place at the University of Sussex on campus premises using password protected computers accessed by the Chief Investigator and both supervisors.

A42. Who will have control of and act as the custodian for the data generated by the study?

IRAS Form		Reference: 16/NW/0610	IRAS Version 5.3.1
	Title Forename/Initials	Surname	
	Miss Rachel	Clarke	
Post	PhD Student		
Qualifications	BSc Psychology, MSc Mental Health Studies		
Work Address	School of Education and Social Work and The School of Psychology		
	The University of Sussex		
	Falmer, Brighton		
Post Code	BN1 9RH		
Work Email	rc362@sussex.ac.uk		
Work Telephone	07902651500		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ○ 6 – 12 months
- ◉ 12 months – 3 years
- Over 3 years

If longer than 12 months, please justify:
The sponsor and funders (ESRC) has no exact timescale for the storage of personal data, but make the key point to store the data securely and not for longer than necessary, in line with the Data Protection Act (1998). Personal contact details will be used to send a summary of findings to participants who request one.

A44. For how long will you store research data generated by the study?

Years: 10
Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended *Say where data will be stored, who will have access and the arrangements to ensure security.*

Research data will be stored at Sussex Partnership NHS Foundation Trust (SPT) premises for the 10 year duration in line with Sussex Partnership policy. The Sussex Partnership R&D department has archiving facilities for storing research data for this period.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

◉ Yes ○ No

Please give details, or justify if not registering the research.
The research will be registered on the UKCRN NIHR Portfolio database.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☑ Internal report
- ☑ Conference presentation
- ☑ Publication on website
- ☐ Other publication
- ☑ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

We will not use identifiable personal data. ID numbers will be used to protect participants' identities and quotes from interviews will be edited to ensure identifiable information is omitted before publication.

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.
Participants will receive a written summary of the findings at the end of the research study, which will include a description of how these findings will be fed back to policy.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- [x] Independent external review
- [ ] Review within a company
- [ ] Review within a multi-centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [x] Review within the research team
- [x] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The protocol has been subjected to scientific critique by: a) the educational supervisors; a) the PPI - Dementia Consultation Group; and b) the School of Education and Social Work at Sussex University via Mini-Viva and annual review. The PPI have recommended revisions to the study (see section A14-1) which has been included in the study design. A Mini-Viva was also conducted on 18th April 2016 to assess the quality of the study design. Following the Mini-Viva, revisions to the study were suggested and implemented.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? *Tick as appropriate:*

- [ ] Review by independent statistician commissioned by funder or sponsor
- [ ] Other review by independent statistician
- [ ] Review by company statistician
- [ ] Review by a statistician within the Chief Investigator's institution
- [ ] Review by a statistician within the research team or multi-centre group
- [x] Review by educational supervisor
- [ ] Other review by individual with relevant statistical expertise
- [x] No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Professor	Jennifer	Rusted
Department	School of Psychology		
Institution	University of Sussex		
Work Address	Pevensey 1 2B21		

Brighton

Post Code BN1 9QG
Telephone 01273 678325
Fax
Mobile
E-mail j.rusted@sussex.ac.uk

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome measures will be a comparative analysis of the perceived factors associated with psychological wellbeing, based on 1. questionnaire data and 2. content analysis to explore the narratives of working family carers in this study.

A58. What are the secondary outcome measures? *(if any)*

The secondary outcome measures are changes in performance on the objective measure of prospective memory.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	50
Total international sample size (including UK): 50	
Total in European Economic Area:	50

Further details:
We aim to recruit approximately 30-50 working family carers. Previous studies with non-working family carers have also used much smaller samples using only quantitative assessments of psychological wellbeing (Bristow et al., 2008; Nicolaou et al., 2010; Braun et al., 2010; Ervin & Pallant, 2015).

For the extraction of secondary data from the linked study, there will be between 300 and 700 working and non-working family carers of approximately 1000 family carers.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The sample will be relatively small due to the characteristics and availability of participants in this area. As evidenced by the national longitudinal IDEAL study size (300+ working family carers out of 1000 carers), the sample is unique and less common than non-working family carers of a person with dementia. Therefore, the sample size of 50 has been selected as optimal.

A61. Will participants be allocated to groups at random?

Yes No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Quantitative data from questionnaires: An exploratory factor analysis will be conducted initially to identify which questions load on the variables of: psychological wellbeing, work and life balance and everyday functioning. Logistic regression analysis will be performed to understand the relationships between these variables associated and mediators associated with coping mechanisms and instrumental/emotional support. Comparative analyses will then be conducted between working and non-working family carers in the IDEAL study to explore whether a difference in psychological wellbeing exists in a larger cohort.

Qualitative data: Data collected from interviews will be analysed using conventional content analysis to explore the narratives of working family carers. This data analysis involves repeatedly reading the data to obtain a sense of the whole story. Data is then read word by word to derive codes from text which captures key concepts. The following stage is to make notes on first impressions and thoughts, and creating codes that reflect key thoughts. These codes are organised into different categories based on how they are linked and then sorted into meaningful clusters. Larger subcategories are organised into a smaller number of categories and definitions for each category, subcategory, and code are developed.

The final analysis will involve the comparison of quantitative and qualitative findings to model the relationship between sustained psychological wellbeing, everyday functioning and work and life balance. This will be achieved by convergent parallel design, which will bring together the quantitative and qualitative strands of the study and merge the results into an overall interpretation.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

Title Forename/Initials Surname

Post
Qualifications
Employer
Work Address

Post Code
Telephone
Fax
Mobile
Work Email

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: NHS or HSC care organisation

Commercial status:

- ○ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- Other

If Other, please specify:

Contact person

Name of organisation	Sussex Partnership NHS Foundation Trust
Given name	Taffy
Family name	Bakasa
Address	Sussex Partnership Research and Development, Millview Hospital, Nevill Avenue
Town/city	Brighton
Post code	BN3 7HY
Country	UNITED KINGDOM
Telephone	01273 265909
Fax	
E-mail	taffy.bakasa@sussexpartnership.nhs.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

☑ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☐ No application for external funding will be made

What type of research project is this?

○ Standalone project
◉ Project that is part of a programme grant
○ Project that is part of a Centre grant
○ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

Please give details of funding applications.

Organisation	Economic and Social Research Council
Address	Polaris House North Star Avenue Swindon
Post Code	SN2 1UJ
Telephone	01793 413000
Fax	
Mobile	
Email	esrcenquiries@esrc.ac.uk

Funding Application Status: ◉ Secured ○ In progress
Amount: 4,802,287.00

Duration
Years: 4
Months:

If applicable, please specify the programme/ funding stream:

What is the funding stream/ programme for this research project?

Research Grant, Research Programmes
This PhD is directly funded from the Living well and enhancing active life: the IDEAL study grant award; Ref: ES/I001853/1

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1)? 2 *Please give details of subcontractors if applicable.*

○ Yes ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials	Surname
	Miss Taffy	Bakasa
Organisation	Sussex Partnership NHS Foundation Trust	
Address	R&D Department	
	Sussex Education Centre, Mill View Hospital Site	
	Nevill Avenue, Hove	
Post Code	BN3 7HZ	
Work Email	researchgovernance@sussexpartnership.nhs.uk	
Telephone	01273 265909	
Fax		
Mobile		

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A68-2. Select Local Clinical Research Network for NHS Organisation identified in A68-1:

Kent, Surrey and Sussex

For more information, please refer to the question specific guidance.

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2016
Planned end date: 30/11/2017
Total duration:
Years: 1 Months: 3 Days:

A71-1. Is this study?

- (•) Single centre
- ( ) Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

- [x] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?

( ) Yes (•) No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

- [x] NHS organisations in England 1
- [ ] NHS organisations in Wales
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Joint health and social care agencies (eg community mental health teams)
- [ ] Local authorities
- [ ] Phase 1 trial units
- [ ] Prison establishments
- [ ] Probation areas
- [ ] Independent (private or voluntary sector) organisations
- [ ] Educational establishments
- [ ] Independent research units
- [ ] Other (give details)

Total UK sites in study:	1	

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

Yes No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The research is being monitored and audited by both supervisors, an annual internal review at the University of Sussex and the linked Living Well with Dementia study. The first review took place on 18th April 2016 as a Mini Viva to assess the study design. The annual review assessed the progress of the study. The linked Project Management group meet on a bi-annual basis and have regular teleconferences to assess all matters regarding the progress of the IDEAL study and the linked project. The first meeting took place on 28 -29 January 2016. The second meeting will take place in July 2016 (see also A54-1).The sponsor conducts annual research monitoring of all studies.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:** In this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☑ NHS indemnity scheme will apply (NHS sponsors only)

☐ Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☑ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☐ Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at

these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

Yes No Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Investigator identifier	Research site	Investigator Name	
IN2			
(●) NHS site		Forename	Rachel
( ) Non-NHS site		Middle name	
		Family name	Clarke
Country: England		Email	rc362@sussex.ac.uk
		Qualification (MD...)	MSc, BSc
		Country	UNITED KINGDOM
Organisation name	SUSSEX PARTNERSHIP NHS FOUNDATION TRUST		
Address	SWANDEAN		
	ARUNDEL ROAD		
	WORTHING WEST SUSSEX		
Post Code	BN13 3EP		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply. May be sent by email to REC
    - members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◯ Chief Investigator

- ◯ Sponsor
- ◯ Study co-ordinator
- ◯ Student
- ◯ Other – please give details
- ◯ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by miss rachel clarke on 25/07/2016 11:21.

Job Title/Post:	PhD Student
Organisation:	University of Sussex
Email:	rc362@sussex.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Miss Taffy Bakasa on 25/07/2016 11:31.

Job Title/Post:	Lead Governance Officer
Organisation:	Sussex Partnership NHS FT
Email:	taffy.bakasa@sussexpartnership.nhs.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by JENNIFER RUSTED on 25/07/2016 11:59.

Job Title/Post:	professor
Organisation:	sussex university
Email:	j.rusted@sussex.ac.uk

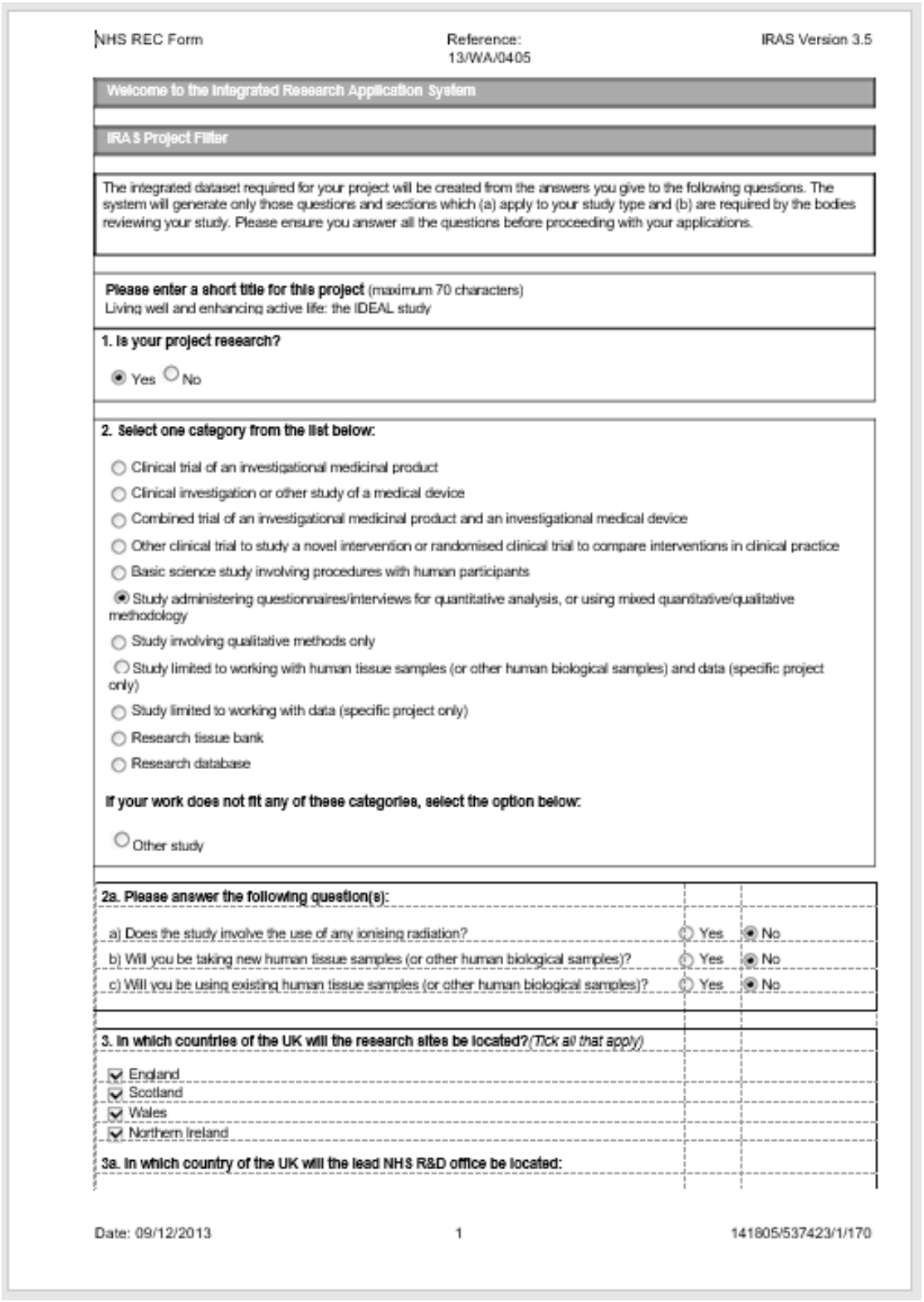
Academic supervisor 2

This section was signed electronically by DR. Henglien Lisa Chen on 26/07/2016 11:05.

Job Title/Post:	Lecturer in Social Work, Wellbeing and Social Care
Organisation:	University of Sussex
Email:	h.l.chen@sussex.ac.uk

Appendix XVII:

IDEAL IRAS application



NHS REC Form | Reference: 13/WA/0405 | IRAS Version 3.5

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Living well and enhancing active life: the IDEAL study

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
(●) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
( ) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):		
a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- [x] England
- [x] Scotland
- [x] Wales
- [x] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

Date: 09/12/2013 | 1 | 141805/537423/1/170

- ○ England
- ○ Scotland
- ◉ Wales
- ○ Northern Ireland
- ○ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

◉ Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

◉ Yes ○ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

○ Yes ◉ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study

NHS
Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Living well and enhancing active life: the IDEAL study

Please complete these details after you have booked the REC application for review.

REC Name:
North Wales - West

REC Reference Number:
13/WA/0405

Submission date:
09/12/2013

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Improving the experience of dementia and enhancing active life: the IDEAL study

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Professor	Linda	Clare
Post	Professor of Clinical Psychology and Neuropsychology		
Qualifications	MA, MSc, PhD, CPsychol, FBPsS		
Employer	Bangor University		
Work Address	School of Psychology		
	Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
Work E-mail	l.clare@bangor.ac.uk		
* Personal E-mail			
Work Telephone	01248388178		

* Personal Telephone/Mobile
Fax 01248382599

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project? *This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.*

	Title	Forename/Initials	Surname
	Mr	Hefin	Francis
Address	School of Psychology		
	Bangor University		
	Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	h.francis@bangor.ac.uk		
Telephone	01248388339		
Fax	01248382599		

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:	
Protocol Version:	
Protocol Date:	
Funder's reference number:	ES/I001853/1
Project website:	

Additional reference number(s):

Ref Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK*

Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

Living well with dementia, whether as a person with dementia or primary (usually family) carer, can be understood as maximising life satisfaction, reaching one's potential for well-being, and experiencing the best possible quality of life. Enabling people with dementia and primary carers to live well with dementia is a key UK policy objective, but there is little guidance as to how this should be achieved. This project aims to identify what helps people to live well, or makes it difficult to live well, with dementia. We anticipate that for both people with dementia and carers the ability to live well with dementia will be influenced by social and psychological resources, by the challenges presented by dementia, and by the way in which people adapt to these challenges. We will find out about the way in which social and psychological resources influence the process of adapting to the challenges presented by dementia and the extent to which people remain able to engage in activities and participate in the community. Over a two-year period we will recruit 1500 people with mild to moderate dementia from all areas of the UK. We will also include a primary carer wherever possible, and we expect to recruit about 1000 carers. All the participants will be visited at home and asked to provide information about things that may influence their life satisfaction, well-being and quality of life. This will yield numerical data that we will analyse statistically. We will visit all the participants on two more occasions, one year apart, to find out how their situation and well-being change over time. A smaller group composed of those whose ability to live well improves or declines between the first and second visits will be interviewed in more depth to enrich the understanding gained from the statistical analyses.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

We think that the main ethical issues are involvement, consent, confidentiality, protection of well-being, risk and benefit, and vulnerability.

Involvement. The proposed study has already involved people with dementia and carers in the selection of the overall topic, including contributions to design and dissemination of research. This will be extended to involvement of people with dementia and carers in advisory groups through our PPI strategy.

Consent. Our procedures will address the following issues:
1. Provision of information. This will be done using written information and clarified by the researcher when meeting face-to-face. Information provided in advance of formal consent being obtained will be clear and easy to understand.
2. Indication of voluntary nature. The information will indicate that the participant can withdraw at any time from the project, not affecting any treatment or professional support.
3. Capacity. Capacity is defined in context as the ability to understand the information provided, retain and weigh up such information sufficiently and for a long enough time to make a decision, and to understand the consequences of that decision. Participants should also be able to understand the benefits, risks and costs associated with participating in the research and must be able to communicate their understanding. Our researchers will be trained in PwD capacity issues, and assessments will be formalised using a checklist, with detailed notes. If there are doubts about capacity at initial assessment, the participant will not be included. It is expected that people with dementia in the mild to moderate stages will normally have capacity to consent, but as this is a longitudinal study, it is possible that participants may lose capacity over the course of the study. Therefore, on entry to the study, a personal consultee will be identified for each PwD, who can advise on continued participation if capacity is lacking at the time of the follow ups.

Confidentiality. Procedures will be in place to ensure that participants cannot be personally identified from any data source and that the information they provide is kept confidential, except where this is overridden by concerns about vulnerability.

Well-being. Our procedures will be designed to protect well-being, including making participant involvement a positive experience. Researchers will be trained in working with people with dementia and carers, and will be sensitive to their concerns and to any change during a research interview or between the baseline and follow up time points. This includes sensitivity to the issue of continued consent within an interview and the general needs of the participant, including dealing with occasional distress. The assessment methods used (questionnaires and brief cognitive tests) have been used previously with people with dementia and carers and found to be acceptable. In addition to overall consent issues, some participants may not wish to provide responses to particular questions and this will be handled sensitively with no coercion.

Risk. The risks to the participants can technically be defined as 'minimal,' with the anticipated level approximately the

same as in routine psychological assessments relating to diagnosis and management. Examples of possible negative experiences include finding questionnaires boring or repetitive, not enjoying having to respond to questionnaires and experiencing some distress when considering answers to particular questions or attempting cognitive tests. The researchers will be trained to deal with these aspects and to create an overall positive experience, for example by establishing good rapport with the person with dementia and carer, and by sequencing aspects of the assessment in an optimal manner.

Vulnerability. People with dementia are potentially vulnerable, and as such the researchers will have a duty of care to deal with issues giving rise to serious concern. The researchers will have training in this regard and will be familiar with local Protection of Vulnerable Adults procedures. These indicate the steps to be taken if serious concerns arise, including who to inform. A sample POVA protocol is provided with this application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

- ☐ Case series/ case note review
- ☐ Case control
- ☑ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

1. How do social and psychological resources, and adaptation in response to dementia-related and other challenges, influence the ability to live well for people with dementia and primary carers, and how do people with dementia and primary carers each influence the other's ability to live well with dementia?
2. How do changes over time in social and psychological resources, dementia-related and other challenges, and adaptation affect the extent to which people with dementia and primary carers feel they are able to live well with dementia?
3. What do people with dementia and primary carers believe helps or hinders the possibility of living well, and what factors are particularly important to them as regards being able to live well with dementia?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Not applicable.

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Enabling people with dementia and their family carers to live well with dementia is a key UK policy objective. Policy recommendations emphasise the importance of understanding the personal and social experience of people with dementia and family carers; however, there is a need to articulate more fully what it really means to 'live well' in the context of the challenges dementia brings for individuals and relationships, and to identify factors that influence the ability to live well. The concept of 'living well' has rarely been discussed explicitly in the scientific literature relating to dementia. Where it is mentioned, it is equated with experiencing a good quality of life (QoL). However, this does not

capture all the elements involved in living well. The World Health Organisation defines living well with chronic illness and disability as 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being', and notes that 'for each individual…to live well takes on a unique and equally important personal meaning, which is defined by a self-perceived level of comfort, function and contentment with life.' Living well in this definition is a broader construct than QoL, incorporating concepts of well-being and life satisfaction, and reflecting the importance of social and psychological resources and the potential for social participation. Few studies have directly examined subjective well-being and life satisfaction in dementia. QoL has been more extensively studied, but researchers still argue that little is known about the factors that influence QoL for people living with dementia and how these change over time as dementia progresses. Taken together, demographic variables, symptoms, concurrent health conditions, and degree of carer burden do not sufficiently explain the reasons why some people, whether people with dementia or carers of people with dementia, experience good and others poor QoL. In addition, although it is evident that people with dementia and primary carers respond in diverse ways, little is known about how they make sense of and adapt to the condition and to the changes they experience over time, or about the reciprocal influences between each member of the dyad. Therefore, we need to take a broader perspective, and to move from a primarily medical or disease- oriented focus to a more psychologically- and socially-oriented understanding which acknowledges the role of differences in personal and social resources, social circumstances and social environments. Our study will be the first to construct a novel and detailed longitudinal data set based on a large cohort of people with dementia and primary carers that focuses specifically on social and psychological factors in order to provide scientific evidence to inform policy and practice. The dementia trajectory encompasses enormous variation from the earliest stages to the end of life, and what constitutes living well differs across this trajectory. We will focus on people with dementia who, on entry to the study, are living in their own homes with mild or moderate dementia, and follow them and their carers over time, observing whether and how their situation changes, and monitoring the progression of dementia, in order to identify the factors that influence their ability to live well as dementia progresses.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This is a longitudinal cohort study. We will recruit 1500 people with dementia from all over the UK, and wherever possible we will also recruit a family carer of the person with dementia; we expect to recruit about 1000 carers. For those who express interest following initial contact, a home visit will be arranged in order to discuss participation further and, where appropriate, obtain informed consent for entry to the study. Non-responses to the initial contact will be followed up by research network staff once to compensate for the possibility that letters and messages could be mislaid due to memory difficulties. The initial assessment will then be completed over two further home visits each lasting no more than 2 hours, and will involve responding to questionnaires and, in the case of the person with dementia, completing some brief cognitive tests. Each participant will be reassessed 12 and 24 months later, after ensuring continued consent. While we anticipate two home visits at each time point, the number and duration of visits is flexible depending on the preferences of the participants. A subgroup of 30 people with dementia and 30 carers showing changes on key measures between the first (baseline) and second (12 month) assessments will be invited to engage in an additional detailed interview. This process will be repeated with 30 people with dementia and 30 carers showing changes on key measures between the second (12 month) and third (24 month) assessments.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- [x] Design of the research
- [x] Management of the research
- [ ] Undertaking the research
- [ ] Analysis of results
- [x] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
Proposal development: People with dementia and carers of people with dementia contributed their views and perspectives through the Alzheimer's Society Research Network and the networks of Innovations in Dementia CIC, and the information they provided influenced the focus of the study.
Study delivery and dissemination: We will set up and fully engage with an independent Project Advisory Network consisting of people with dementia, carers and other volunteers. This will be facilitated by Innovations in Dementia and the Alzheimer's Society and will operate in a flexible manner, providing advice and direct input in a number of key areas including selection of questionnaire measures, training of project staff, development of information materials,

and preparation of project outputs. We will also set up a Project Advisory Group which will hold regular formal meetings, with representation from the advisory network and other independent advisers. The advisory group will in turn be represented on our project management group.

PPI for this project has been developed in accordance with Involve guidance.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

People with dementia must have a clinical diagnosis of dementia (any sub-type), must be in the mild to moderate stages as indicated by an MMSE score of 15 or above or an appropriate score on an equivalent screening measure such as ACE-III or MOCA, and must be able to give informed consent on entry to the study.

Primary carers will be the designated primary carers of people with dementia who meet inclusion criteria.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

People with dementia will be excluded if they are known to have a co-morbid terminal illness on entry to the study and if there is any known potential for home visits to pose a significant risk to research staff.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Consent visit	1	0	1	Research network staff; home visits
Initial assessment - two sessions	1	0	4 hours	Research network staff; home visits
12 month assessment - two sessions	1	0	4 hours	Research network staff; home visits
24 month assessment - two sessions	1	0	4 hours	Research network staff; home visits

A21. How long do you expect each participant to be in the study in total?

Two years.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Participants will be asked to give their time to complete the assessments. We consulted about this during the proposal development phase and the feedback from people with dementia, carers, and clinicians indicated that the level of burden was felt to be acceptable. We do not anticipate any adverse effects arising from participation in the study.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

○ Yes ◉ No

A24. What is the potential for benefit to research participants?

There will be no direct benefit to research participants; however, participants may value the opportunity to contribute to knowledge in this area as there is potential for the findings to influence policy and practice, and may enjoy the contact with the researchers.

A26. What are the potential risks for the researchers themselves? *(if any)*

We do not think that the research poses any specific risks to the researchers. Appropriate policies and procedures regarding lone working and undertaking home visits will be followed.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Participants will be recruited from Memory Services, other specialist clinics (e.g. movement disorders clinic), and from databases listing people with dementia who are interested in research participation, through UK research networks (currently DeNDRoN in England, NISCHR CRC in Wales, the Scottish Dementia Network and the Northern Ireland Clinical Research Network), also drawing on contacts with community mental health teams, GP practices, social services and voluntary sector groups as appropriate. Research network staff, who are NHS employees, will recruit participants in their local areas.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

◉ Yes ○ No

Please give details below:
During the process of participant identification and recruitment, the research team itself will not have access to any personal information of patients. Research network staff (e.g. from DeNDRoN, NISCHR, SDN, or NICRN), who are NHS employees integrated with clinical care teams, will work in conjunction with the clinical teams in identifying potential participants. They may where appropriate, in accordance with local agreements and policies, be given access to names and contact details, and to information relating to our inclusion and exclusion criteria, in order to assist the clinical teams in screening for potential participants.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

○ Yes ◉ No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ◉ No

A29. How and by whom will potential participants first be approached?

Potential participants will be approached initially by an NHS staff member, either face-to-face during clinic visits, or by letter or telephone call.

A30-1. Will you obtain informed consent from or on behalf of research participants?

(●) Yes ( ) No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Consent from people with dementia, and where applicable from carers, will be taken by a member of research network staff during a home visit. Written information about the study, prepared in a readily understandable format, will be provided in advance of this visit. The information will indicate that the participant can withdraw from the study at any time and that this will not affect the care s/he receives. The voluntary nature of consent will also be emphasised by the research network staff member during the visit. The research network staff taking consent will be trained in capacity issues and will use a checklist to formalise their evaluation of capacity and ensure that the participant is able to understand the information provided, use this information to reach a decision, and demonstrate an understanding of the benefits and costs of taking part. People with mild to moderate dementia are normally expected to have capacity to consent, but if there are any doubts about capacity to consent at the point of entry to the study, the participant will not be included.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(●) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

As long as they need, but at least one week.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

The research networks would draw on local specialist resources where necessary.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

Information about the study will be available in both English and Welsh.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

( ) The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

( ) The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

(●) The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

We anticipate that some participants with dementia will lose capacity to consent during the course of the study. Therefore, for each participant joining the study, a personal consultee will be identified who can advise on the appropriateness of continued participation if capacity is lacking at the time of follow-up. If the consultee advises against continued participation, the participant will be withdrawn, but data already collected with consent would be retained and used in the study.

Please complete Part B, Section 6, giving further information about arrangements for including adults unable to consent for themselves.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☐ Manual files including X-rays
  - ☑ NHS computers
  - ☐ Home or other personal computers
  - ☑ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

Further details:

The research network staff will use personal contact details in the course of arranging to visit participants at home, and will need to store these details on NHS computers. Participants will of course have provided these details themselves, or agreed to their provision, by indicating an interest in finding out more about the study. All participants will be asked during the consent process for permission to forward their contact details (name, address, telephone number and email address) to the research team at Bangor University. Participants will also be asked for permission to contact them should we wish to invite them to engage in the qualitative interview component of the study. These interviews will be audio-recorded and transcribed. In writing up the findings of the qualitative component of the study, it is likely that (anonymised) direct quotations will be used, and participants' consent will be sought for this during the consent procedure.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and*

procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

All data will be anonymised. Each participant will be assigned an identification number which will be used on all documents, data files and transcripts. The participant identification number will be recorded on the consent form, which will be the only point at which this can be linked to the participant's personal details. Consent forms will be stored securely in locked filing cabinets in research network offices. A copy of the consent form will also be stored securely in locked filing cabinets at Bangor University. All participants will be asked during the consent process for permission to forward their contact details (name, address, telephone number and email address) to the research team at Bangor University.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The research network staff will have access to participants' addresses, telephone numbers and (where relevant) email addresses during the course of the study as they will be visiting participants at home. Participants will themselves have provided these details, or will have agreed to their contact details being provided, and hence consent is implied. All participants will be asked during the consent process for permission to forward their contact details (name, address, telephone number and email address) to the research team at Bangor University. Participants will also be asked for permission to contact them should we wish to invite them to engage in the qualitative interview component of the study.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ○ 6 – 12 months
- ○ 12 months – 3 years
- ◉ Over 3 years

If longer than 12 months, please justify:
Personally identifiable information will be retained after completion of the study only where the participant has consented to retention of details for potential further follow up.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will receive a small token of appreciation in the form of a shopping voucher to the value of £10 when they complete the assessment at each time-point. This was a requirement of the funder.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

◉ Yes ○ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

◉ Yes ○ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

◉ Yes ○ No

Please give details, or justify if not registering the research.
The research will be registered on the NIHR Clinical Research Network Portfolio, the NISCHR Clinical Research Portfolio, the Scottish Dementia Clinical Research Network Portfolio, and the Northern Ireland Clinical Research Network Portfolio.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☐ Internal report
- ☑ Conference presentation
- ☑ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

Please see the 'Pathways to Impact' document which forms part of the proposal for a full overview of what is planned.

A53. Will you inform participants of the results?

◉ Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be kept informed of developments in the study with a twice-yearly newsletter which will include details

of emerging findings.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- [x] Independent external review
- [ ] Review within a company
- [ ] Review within a multi-centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [ ] Review within the research team
- [ ] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
This study was funded through an application to the ESRC/NIHR Large Grants Dementia Themed Call. The review process was as follows: (a) an outline proposal was submitted, checked for eligibility, sent out for peer review, reviewed by the funding panel, and shortlisted; (b) a full proposal which had been peer-reviewed within the Bangor University College of Health and Behavioural Sciences was submitted to the funder, sent out for peer review, reviewed by the funding panel, and shortlisted; (c) members of the research team attended an interview at which they defended the proposal before a panel.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? *Tick as appropriate:*

- [ ] Review by independent statistician commissioned by funder or sponsor
- [ ] Other review by independent statistician
- [ ] Review by company statistician
- [ ] Review by a statistician within the Chief Investigator's institution
- [x] Review by a statistician within the research team or multi-centre group
- [ ] Review by educational supervisor
- [ ] Other review by individual with relevant statistical expertise
- [ ] No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Mrs	Rhiannon	Whitaker
Department	North Wales Organisation for Randomised Trials in Health (NWORTH)		
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	Bangor, Gwynedd		
Post Code	LL57 2PZ		
Telephone	01248382597		

Fax	01248382229
Mobile	
E-mail	r.whitaker@bangor.ac.uk

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

Ability to 'live well' with dementia for the person with dementia, as indexed by responses to short versions of questionnaires assessing quality of life, life satisfaction, and well-being:
Activity and Affect Indicators of Quality of Life: Patient Activity
Scale Quality of Life in Alzheimer's disease EQ5D

Satisfaction with Life Scale
WHO-5 Well-Being Index

A58. What are the secondary outcome measures? *(if any)*

Ability to 'live well' with dementia for the primary carer, as indexed by responses to short versions of questionnaires assessing quality of life
WHOQOL-BREF
EQ5D
Satisfaction with Life Scale
WHO-5 Well-Being Scale

Measures of psychological and physical resources for the person with dementia, with questions taken from the following sources:
Cognitive Lifestyle Score
Ryff Scales of Psychological Well-Being
Mini-IPIP
Rosenberg Self-Esteem Scale
Generalized Self-Efficacy Scale
Flexible Goal Adjustment & Tenacious Goal Pursuit-Short version
Life Orientation Test-Revised
Decision-Making Involvement Scale
Religion and spirituality
Identity
Philadelphia Geriatric Center Morale Scale
Subjective health
International Physical Activity Questionnaire-Short Form
Sedentary questionnaire

Measures of social and cultural resources for the person with dementia, with questions taken from the following sources:
Social capital ONS CORE items
Access to social capital: Resource Generator-UK; Resource-Name Generator
Cultural capital
Lubben Social Network Scale
Quality of social support
Positive Affect Index
Client Service Receipt Inventory
Satisfaction with services used
Social comparison
Dignity
Housing, neighbourhood, and community
Financial: Income

Measures of dementia-related challenges and adaptation for the person with dementia, with items taken from the following sources:
Addenbrooke's Cognitive Examination III
The Test for Severe Impairment
Functional Activities Questionnaire
Representations and Adjustment to Dementia Index (RADIX)

Stigma and Social Impact of Disease
Geriatric Depression Scale-10
EQ-5D-3L
Falls; Sensory Impairment; Sleep
Loneliness Scale
Global Deterioration Scale/Functional Assessment Staging(completed by the interviewer)
Neuropsychiatric Inventory Questionnaire
The Dependence Scale
Charlson Co-morbidity Index

Measures of psychological, physical, social and cultural resources for the carer, with questions taken from the following sources:
Ryff Scales of Psychological Well-Being
Rosenberg Self-Esteem Scale
Generalized Self-Efficacy Scale
Flexible Goal Adjustment & Tenacious Goal Pursuit
Life Orientation Test-Revised
Social comparison question
Mini-IPIP
Religion and spirituality
International Physical Activity Questionnaire-Short Form
Subjective health
Sedentary questionnaire
Social capital: ONS CORE items
Access to social capital: Resource Generator-UK
Lubben Social Network Scale
Quality of social support
Positive Affect Index
Client Service Receipt Inventory (CSRI)
Satisfaction with services used

Measures of dementia-related challenges and adaptation for the carer, with items taken from the following sources:
Role Captivity
The Modified Social Restriction Scale
Relative Stress Scale
Positive aspects of caregiving
Sensory impairment
Loneliness Scale
Center for Epidemiologic Studies Depression Scale-Revised
EQ-5D-3L
Caregiver coping
Caregiving Competence Scale

The questions will be compiled to form four questionnaires; one for the person with dementia, one for the primary carer to complete about the person with dementia, one for the primary carer to complete on his/her own behalf and one for the interviewer to complete about the person with dementia with information obtained from the carer. At present, we have prepared a first version of each of these, which is provided with this application. These first versions will be the subject of consultation with our PPI networks and will also be piloted with volunteers, with the aim of ensuring acceptability. We also aim through this process to reduce the number of items included in the final versions; item reduction will take account of available evidence (e.g. factor analyses, item-total correlations). Once this has been achieved, the questionnaires will be formatted in a manner appropriate for administration by research network staff, which will also allow for carers, where appropriate, to complete some sections by themselves. These final versions will be forwarded to the Committee once available. As this is a longitudinal study it is important to take account of the effects of dementia progression on ability to respond over time; therefore, for each key construct, a single item question has been, or will be, identified that can be asked of participants whose dementia has progressed to the point where it is only possible to respond to a smaller number of items. In addition, by collecting carer proxy ratings from the outset, we can control at later time points for observed differences in perspective between the person with dementia and the carer, should the person with dementia become unable to provide self-ratings.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 2550
Total international sample size (including UK):

Total in European Economic Area:

Further details:
We aim to recruit 1500 people with dementia. Where possible we will also recruit a primary carer of the person with dementia, and we expect to recruit approximately 1050 carers.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The proposed sample size was determined by taking into account a combination of factors: requirements for the statistical analyses we plan to undertake; estimates of potential recruitment from the research networks; time involved in interviewing participants with dementia and carers; and costs of participant recruitment and assessment. The selected sample size was felt to provide an optimal balance between these different factors. The planned statistical analyses include structural equation modelling (SEM). This method requires a large sample as it involves building a multivariate model using part of the data and then testing it against the data from the rest of the sample. A sample size of 1050 was identified as meeting requirements. This large sample size will be sufficient for other, less data-heavy analysis methods and will allow for a range of sub-group analyses. As the required sample size is 1050, we are in fact planning to over-sample to allow for attrition. We will obtain baseline data from 1500 people with dementia, representing 30% oversampling. Based on prior experience with our own studies and on evidence from the research literature, we have allowed for 30% attrition. We also plan interim examination of the range of MMSE scores at baseline to enable us if necessary to adjust the sampling plan in order to ensure that we have the desired range of dementia severity at baseline. Our sampling strategy is informed by robust population estimates on the key parameters of dementia sub-type, age, gender, living situation and relationship with primary caregiver. We have obtained agreement from 17 research networks covering all areas of the UK to recruit for this study and we will negotiate tailored recruitment targets with each network, reflecting the population covered by that network, at the start of our study. To ensure that we are achieving our target sample we will examine our Time 1 (T1) data at pre-determined times (3 months, 6 months, 12 months, 18 months) to evaluate the distribution of these parameters within our sample, along with the distribution of MMSE scores indicative of dementia severity, and adjust recruitment targets if necessary. At these time points we will also assess our sample in relation to indices of social deprivation (by postcode) and, if necessary, adjust our recruitment targets to sample more intensively from areas with higher or lower social deprivation. We anticipate conducting sub-group analyses with T1 data as follows: age, gender, dementia sub-type, living situation (alone vs. with others), and carer relationship (spouse vs. child). At Time 3 (T3), following testing of our main models, we will run sensitivity analyses to examine how well these models fit the data from smaller sub-groups (early-onset dementia and rarer sub-types of dementia). To undertake this analysis will require a minimum of 30 individuals per sub-group at T3. Employing population estimates from Dementia UK and/or appropriate research studies (see Table 1), we have estimated the anticipated numbers in our sample at baseline and at T3 assuming an attrition rate of 30%. Using this protocol indicates that we will have sufficient numbers in most sub-groups with the exception of people with Parkinson's disease dementia (PDD) and fronto-temporal dementia (FTD), and people with early-onset dementia, where we will need to over-sample at baseline to increase numbers in these groups to 45 each. This will be achieved by specifically targeting movement disorders clinics where people with PDD are seen, specialist memory clinics known to have a particular focus on FTD, and specialist services for working-age individuals with dementia. We have estimated an attrition rate of 30% over the course of the study but we acknowledge that this may vary according to participant characteristics and may be problematic if attrition rates are higher for sub-groups where baseline numbers are small. To address this we will monitor attrition rates in the first 6 months of Time 2 (T2) data collection, as collection of T2 data will begin 12 months before collection of T1 data is complete. Should we identify any unexpected differential attrition rates, we will use this information to adjust T1 recruitment targets for the remaining 6 months of T1 data collection.

A61. Will participants be allocated to groups at random?

○ Yes ◉ No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Quantitative data: In line with our research questions, our analysis plan will proceed in stages. The first stage will focus on the descriptive analysis of Time 1 (T1) data, examination of relationships between key variables and comparisons for relevant sub-groups. We will then progress to model development and testing, initially with cross-sectional and subsequently with longitudinal data. Our basic modelling philosophy will be to develop a selection of credible models, based on the synthesis of statistical evidence from cross-sectional data at T1, theoretical frameworks and results of

qualitative inquiry. We will then test, refine and develop those models taking into account temporal change using the longitudinal data from Time 2 (T2) and Time 3 (T3). The modelling will take variable reduction and parsimony as guiding principles. T1 modelling will allow us to develop the building blocks for subsequent analysis by focusing on the direct relationships within the data. Split sample techniques will be used, so that models can be generated on part of the dataset and tested on the rest, thus combining exploratory modelling with a limited confirmatory analysis. T1-T2 data will then be explored to test and combine the most promising of the models generated in T1 in larger structural equation modelling (SEM) work. Again, split sample techniques will be utilised to validate the findings of the exploratory work. We will have a set of models describing parts of the hypothesised framework available for full testing in the final stage of the project. This modelling will also be checked against existing theoretical frameworks and the results of our qualitative research, so that areas of novelty can be explored and credibility established. T1-T3 data will be used for final model building and testing for sensitivity to sub-groups and other assumptions.

Qualitative data: We will adopt a user-focused, ego-net approach to characterise people's personal social networks. We will map the relations around an individual using name generator questions, for example asking individuals to name key individuals "whom it would be hard to imagine life without" up to a defined maximum number. This information can be added to and elaborated on, for example by asking additional questions to assess the proportion of family members in the network and to discuss the frequency and quality of contact with key people in the network. 'Visualisation of name generators' allows people not only to name individuals but also to give a visual indication of how close they are to other people they have named. One common example is that of a drawing of concentric rings where the individual being interviewed is placed at the centre of the rings and s/he is asked to position the names in different places on the rings (either close to him/her and each other or further apart). The interviewer can then ask further in-depth questions about the different people in the rings. Visualisation techniques offer a commonly-used basis for structuring a qualitative interview. We will undertake intensive piloting work to identify the best ways of eliciting this information when interviewing people with dementia and their carers, in order to allow us to build up as detailed a picture as possible of the different strands that make up the complexity of individual networks and the sources of social support for a person with dementia. This will provide different forms of data to be analysed using (i) content and thematic analysis based on indexing and constant comparison within and between cases and (ii) joint analysis of qualitative (contextual) and quantitative data on individual social networks.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials	Surname
	Prof. Ian Rees	Jones
Post	Professor of Sociological Research	
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	Title Forename/Initials	Surname
	Prof. Christina	Victor
Post	Professor of Public Health	
Qualifications	BA, M.Phil, PhD	
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	Title	Forename/Initials	Surname	
	Mrs	Rhiannon	Whitaker	
Post	Senior Research Fellow/ Research Methodologist/ Statistician			
Qualifications	BSc PGCE MSc FSS CStat CSci			
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	Y Wern and Meirion Building			
	Bangor University The Normal Site Holyhead Road Gwynedd			
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	Title	Forename/Initials	Surname	
	Prof.	Roy W.	Jones	
Post	Consultant Geriatrician & Director of RICE			
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	Combe Park, Bath			
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	Title	Forename/Initials	Surname	
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Post	Professor of Neuropsychology			
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	Title	Forename/Initials	Surname	
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	Dr.	James A.	Pickett	
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	Dr.	Jeanette M.	Thom	
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	Title	Forename/Initials	Surname	
	Dr.	John V.	Hindle	
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	Title	Forename/Initials	Surname	
	Prof.	Martin	Knapp	
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	Title	Forename/Initials	Surname	
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Post	Research Fellow			
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Work Email	s.nelis@bangor.ac.uk			
	Title	Forename/Initials	Surname	
	Dr.	Catherine	Quinn	
Post	Research Fellow			
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	Bangor University			
	Bangor			
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Telephone	01248 388359			
Fax	01248 382599			
Mobile				
Work Email	catherine.quinn@bangor.ac.uk			
	Title	Forename/Initials	Surname	
	Dr.	Anthony	Martyr	
Post	Research Officer			
Qualifications	BSc, MSc, PhD			
Employer	School of Psychology, Bangor University			
Work Address	School of Psychology, Bangor University			
	Bangor			
	Gwynedd			
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Telephone	01248 388210			
Fax	01248 382599			
Mobile				
Work Email	a.martyr@bangor.ac.uk			

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

NHS REC Form	Reference: 13/WA/0405	IRAS Version 3.5

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Bangor University, School of Psychology
Given name	Hefin
Family name	Francis
Address	School of Psychology
Town/city	Bangor, Gwynedd
Post code	LL57 2AS
Country	UNITED KINGDOM
Telephone	01248388339
Fax	01248382599
E-mail	h.francis@bangor.ac.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☑ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☐ No application for external funding will be made

What type of research project is this?

- ◉ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ○ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

Please give details of funding applications.

Organisation	Economic and Social Research Council

Address	Polaris House		
	North Star Avenue		
	Swindon		
Post Code	SN21UJ		
Telephone	01793413000		
Fax	01793413001		
Mobile			
Email			
Funding Application Status:		(•) Secured	( ) In progress
Amount:	£4,230,929		
Duration			
Years:	5		
Months:	0		

If applicable, please specify the programme/ funding stream:

What is the funding stream/ programme for this research project?

ESRC/NIHR Large Grants - Dementia Themed Call

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

( ) Yes (•) No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Dr	Rossela	Roberts
Organisation	Betsi Cadwaladr University Health Board		
Address	Research & Development, Clinical Academic Office, Clinical School		
	Ysbyty Gwynedd		
	Bangor		
Post Code	LL57 2PW		
Work Email	rossela.roberts@wales.nhs.uk		
Telephone	01248384384		
Fax	01248384384		
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/01/2014
Planned end date: 31/12/2018
Total duration:

NHS REC Form	Reference: 13/WA/0405	IRAS Version 3.5
Years: 4 Months: 11	Days: 31	

A71-2. Where will the research take place? *(Tick as appropriate)*

- [x] England
- [x] Scotland
- [x] Wales
- [x] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?
○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- [x] NHS organisations in England
- [x] NHS organisations in Wales
- [x] NHS organisations in Scotland
- [x] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Social care organisations
- [ ] Phase 1 trial units
- [ ] Prison establishments
- [ ] Probation areas
- [ ] Independent hospitals
- [x] Educational establishments
- [x] Independent research units
- [ ] Other (give details)

Total UK sites in study: 0

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- [ ] NHS indemnity scheme will apply (NHS sponsors only)
- [x] Other insurance or indemnity arrangements will apply (give details below)

UMAL insurance applies

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- ☑ Other insurance or indemnity arrangements will apply (give details below)

UMAL insurance applies

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- ☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

B. All research other than CTIMPs

In this sub-section, an adult means a person aged 16 or over.

B1. What impairing condition(s) will the participants have?

The study must be connected to this condition or its treatment.

Dementia (any sub-type)

B2. Justify the inclusion of adults unable to consent for themselves. It should be clear why the research could not be carried out as effectively if confined to adults capable of giving consent.

Participants will be able to consent for themselves on entry to the study, but consent is an ongoing process, and as this is a longitudinal study, some participants may lose capacity to consent over the course of their participation. We aim to examine what influences the ability to live well with dementia as dementia progresses, rather than just in the early stages, and by recruiting a sample with mild to moderate dementia at the outset, we expect by the 24 month follow up to have a sample ranging from mild to severe dementia, allowing us to build a comprehensive picture. It is particularly important to understand the influences on ability to live well for people whose dementia has progressed to the extent where they are unable to give informed consent. We therefore need wherever possible to keep people in the study even if they have lost the capacity to consent.

B3. Who in the research team will decide whether or not the participants have the capacity to give consent? What training/experience will they have to enable them to reach this decision?

The research network staff will assess whether participants have capacity to give consent to participation initially, and to continued participation at T2 and T3. They will already have experience of interacting with and assessing people with dementia, and they will receive specific training from the research team. They will use a checklist to ensure that they make a thorough evaluation. At T2 and T3, if the participant is judged to be no longer able to give consent, advice will be sought from the personal consultee identified on entry to the study.

B4. Does the research have the potential to benefit participants who are unable to consent for themselves?

○ Yes ◉ No

B5. Will the research contribute to knowledge of the causes or the treatment or care of persons with the same impairing condition (or a similar condition)?

◉ Yes ○ No

If Yes, please explain how the research will achieve this:

The research will provide new knowledge about what can help to ensure that people with dementia, and carers, are able to live well with the condition. This will inform future policy and practice.

B6. Will the research involve any foreseeable risk or burden for these participants, or interfere in any way with their freedom of action or privacy?

○ Yes ◉ No

Questions B7 and B8 apply to any participants recruited in England and Wales.

B7. What arrangements will be made to identify and consult persons able to advise on the presumed wishes and feelings of participants unable to consent for themselves and on their inclusion in the research?

In England and Wales, a personal consultee will be identified for each participant on entry to the study, and where necessary the personal consultee will be asked to advise on the presumed wishes and feelings of the participant with regard to continuing in the study.

Please enclose a copy of the written information to be provided to consultees. This should describe their role under section 32 of the Mental Capacity Act and provide information about the research similar to that which might be given to participants able to consent for themselves.

B8. Is it possible that a participant requiring urgent treatment might need to be recruited into research before it is possible to identify and consult a person under B7?

○ Yes ◉ No

If Yes, say whether arrangements will be made instead to seek agreement from a registered medical practitioner and outline these arrangements. Or, if this is also not feasible, outline how decisions will be made on the inclusion of participants and what arrangements will be made to seek consent from the participant (if capacity has been recovered) or advice from a consultee as soon as practicable thereafter.

Question B7-1 applies to any participants recruited in Scotland.

B7-1. What arrangements will be made to identify and seek consent from a guardian or welfare attorney or, if there is no such person, from the participant's nearest relative?

In Scotland, an appropriate person will be identified for each participant on entry to the study, and where necessary this person will be asked to advise on the presumed wishes and feelings of the participant with regard to continuing in the study.

Please enclose a copy of the written information to be provided and the consent form to be used. The information sheet should provide information about the research similar to that which might be given to participants able to consent for themselves.

Questions B7-2 and B8-2 apply to any participants recruited in Northern Ireland.

B7-2. What arrangements will be made to consult, and seek assent from, a close relative or other person able to advise on the inclusion of the participant and on their presumed wishes and feelings?

In Northern Ireland, an appropriate person will be identified for each participant on entry to the study, and where necessary this person will be asked to advise on the presumed wishes and feelings of the participant with regard to continuing in the study.

Please enclose a copy of the written information to be provided and the consent form to be used. The information sheet should provide information about the research similar to that which might be given to participants able to consent for themselves.

B8-2. Is it possible that a participant might need to be treated urgently as part of the research before it is possible to seek assent from a close relative or other person?

○ Yes ◉ No

If Yes, say whether arrangements will be made instead to seek agreement from a registered medical practitioner and outline these arrangements. Or, if this is also not feasible, outline how decisions will be made on the inclusion of participants and what arrangements will be made to seek consent from the participant (if capacity has been recovered) or assent from a close relative or other person as soon as practicable thereafter.

B9. What arrangements will be made to continue to consult such persons during the course of the research where necessary?

Where capacity is lost between baseline and 12-month assessments, and the appropriate person has therefore been consulted at the time of the 12-month assessment, this person will be consulted again at the time of the 24-month assessment.

B10. What steps will you take, if appropriate, to provide participants who are unable to consent for themselves with information about the research, and to consider their wishes and feelings?

For participants who are deemed to have lost capacity to consent, the research network staff will nevertheless explain the purpose and nature of the research in simple terms and check the participants' understanding of this information. People with dementia who lack capacity to consent can still express wishes and feelings, and the research network staff will be trained to be sensitive to this and to respond appropriately.

B11. Is it possible that the capacity of participants could fluctuate during the research? How would this be handled?

It is possible that capacity could fluctuate in some cases. We regard consent as an ongoing process that should be continually monitored and checked, and the research network staff will be trained to identify such fluctuations and to respond appropriately.

B12-1. What will be the criteria for withdrawal of participants?

Participants will be withdrawn if they indicate that they do not wish to continue in the study, if they demonstrate a reluctance to engage with and respond to the researcher, or if the personal consultee (or equivalent appropriate person) advises that they should not continue.

B13. Describe what steps will be taken to ensure that nothing is done to which participants appear to object (unless it is to protect them from harm or minimise pain or discomfort).

Participants with dementia who lack capacity to consent will still be able to respond to the researcher if they choose to do so, and to indicate their preferences about whether they wish to answer questions or engage in conversation. The research network staff will be trained to be sensitive to the concerns and reactions of the participants.

B14. Describe what steps will be taken to ensure that nothing is done which is contrary to any advance decision or statement by the participant?

The personal consultee (or equivalent appropriate person) will be asked specifically to indicate whether any advance decisions or other statements apply.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site	Investigator/ Collaborator/ Contact

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

   - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
   - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
   - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
   - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
   - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- ○ Chief Investigator
- ○ Sponsor

- (●) Study co-ordinator
- ( ) Student
- ( ) Other – please give details
- ( ) None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Professor Linda Clare on 06/12/2013 14:51.

Job Title/Post:	Professor of Clinical Psychology and Neuropsychology
Organisation:	Bangor University
Email:	l.clare@bangor.ac.uk
Signature:	.....
Print Name:	Professor Linda Clare
Date:	*(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 05/12/2013 20:55.

Job Title/Post:	School Manager for Psychology
Organisation:	Bangor University
Email:	h.francis@bangor.ac.uk

Appendix XVIII:

IDEAL Consent Form

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY CONSENT FORM FOR PARTICIPANT

Participant identification number:

		Initial here if in agreement
1	I have read and understand the information sheet dated 05/03/15 (version 3) for this study and I have had the opportunity to ask questions about the study.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way.	
3	I understand that if I withdraw from the study the researchers will use the information I have provided up to that point, unless I indicate that I do not want them to.	
4	I understand that the information I give to the researchers will only be used for the purposes of research, and that personal details will be treated in the strictest confidence.	
5	I agree to my GP and (if relevant) my Hospital Consultant being informed that I am taking part in this study.	
6	I understand that if the researchers hear or observe anything that causes serious concern about my health, safety or well-being, they have a duty to inform my GP or another appropriate professional.	
7	I understand that if I lose the ability to decide whether or not I want to continue to take part during the period of the research, the researchers will seek advice regarding continued participation from the personal consultee I have nominated. I understand that if my personal consultee is in favour of me continuing in the study, I will continue in the study as long as I do not object.	
8	I agree that that my personal contact details can be given to the research co-ordinating centre at the University of Exeter, to allow them to contact me about the research.	
9	I agree to the researchers retaining my personal contact details after the end of the study so that they can contact me again in the future should resources become available to find out how well I am doing after a longer period.	
10	I agree that my anonymised data collected during these initial visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	
11	I agree to take part in the study.	

Name of Participant	Date	Signature
Researcher taking consent	Date	Signature

Appendix XIX:

Participant Information Sheet – Full version

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

Participant Information Sheet

I would like to invite you to take part in this study. Before you decide whether to take part, it is important for you to understand why the research is being done and what your involvement would be. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear. Take time to decide whether or not you wish to take part.

What is the purpose of the study? As a key policy objective, the UK government has recognised the need to develop service support for family carers of a person with dementia. As a part of this objective, this study aims to extend our understanding of the factors associated with sustainable work and life balance among 50 family carers in the UK who remain in employment.

Why have I been invited? As a working family carer of a service user within the Sussex Partnership Trust, you have been identified as suitable for this study by a member of the clinical care team.

Do I have to take part? Participation in this study is entirely voluntary. If you agree to take part, you will be asked to sign two consent forms prior to participation.

What will happen to me if I take part? Stage 1 of the research will be completed with myself, the researcher, and you in your home environment. The study will begin firstly, with me asking you a short set of questions which enable me to understand a little more about your background, your caring responsibilities and your occupation. Secondly, I will ask you questions which are designed to find out more about: your psychological wellbeing; your everyday functioning, which includes a short computer task; your work and life balance; and the everyday functioning of the person you are providing care for. Stage 1 of the research last about one hour.

As with stage 1, stage 2 of the research will take place in your home environment. This part of the study aims to explore your experiences of the work and life balance in an interview which will take place around 2 weeks after stage 1. The interview will last for around 1.5 to 2 hours.

What are the possible disadvantages and risks of taking part? In order to reduce any negative impact on you as a participant, you will not be expected to answer any questions that you would prefer not to. As you will be asked to discuss your personal experiences in interviews, you may find some aspects of the interview emotional.

Although I am not a core healthcare professional, you will be provided with information for services which provide support for carers.

What are the benefits of taking part? In the UK, little is known about working family carers of a person with dementia and how they are doing. By taking part in this study, you would enable us to further understand how you and carers like you are managing. Therefore you help is invaluable and will enable us to provide feedback to research and policy in the UK.

Will my taking part in the study be kept confidential? We will follow ethical and legal practice for data protection. All information about you will be handled in confidence within the research team and all data will be anonymised. Consent forms containing personally identifying information will be stored separately and securely from other data. Data will be stored for a minimum of 10 years following completion of the study and then destroyed.

What will happen if I don't want to carry on with the study? You are free to withdraw from the study at any time and without giving a reason. You also have the right to request that your data is withdrawn from the study and destroyed.

What if there is a problem? If you have a complaint about participating in the study, please speak firstly to a member of the research team. In the unlikely event that something goes wrong and you are harmed during the research, the University of Sussex have insurance in place to cover their legal liabilities in the event of injury or damage to the research participants arising from this study.

What will happen to the results of the research? The results are intended to be published. You will not be identified in any publication of the research. You will receive a written summary of the findings at the end of the research study.

Who is organising and funding the research? The research is funded by the Economics Social Research Council (ESRC) and organised in collaboration with the University of Sussex and The Living Well with Dementia national study. This project forms the basis for a PhD which is supervised by Dr Henglien Lisa Chen (Department of Social Work and Social Care) and Professor Jennifer Rusted (Department of Psychology).

Who has reviewed this study? All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the East Midlands - Leicester Central Research Ethics Committee.

Contact Details:

Rachel Clarke (researcher) rc362@sussex.ac.uk 07902 651500
Dr Henglien Lisa Chen (first supervisor) h.l.chen@sussex.ac.uk 01273 873721
Professor Jennifer Rusted (second supervisor) j.rusted@sussex.ac.uk 01273 678325

Appendix XX:

Informed Consent Form

IRAS: 203695 ID number: _____

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

Informed Consent Form

	Please place your initials in the box
I confirm that I have read and understand the Participant Information Sheet (V4 03.12.17) for the above study.	☐
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	☐
I understand that I can request for my data to be withdrawn from the study and destroyed, but this cannot apply to work already published.	☐
I understand my identity and responses (including quotes from stage 2 interviews) will remain confidential and anonymised in published material	☐
I agree to the audio recording of stage 2 interviews	☐
I agree to receiving a summary of the findings	☐
I understand that sections of my medical notes and data collected during the study may be looked at by authorised individuals from the University of Sussex, the research team and regulatory authorities where it is relevant to my taking part in the study. I give permission for these individuals to have access to this information	☐
I have been given a copy of this Consent Form (1 copy for participant and 1 copy for investigator file).	☐
I agree to participate in the study	☐

Your name: _____ Your signature: _____ Date: _____

Signature of researcher: _____ Date: _____

Appendix XXI:

Photography Consent Form

ID number: _____

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

Photography Consent Form

Title of Research Project: Living well with dementia: sustaining psychological wellbeing in working family carers

Researcher: Rachel Clarke

By signing this form

I agree to have my chosen object to be photographed by the researcher or me as I preferred during the study. These photographs will be used in ways I consent in any use of the photographs, I will not be identified by name.

My initials in the boxes bellow indicate the ways I consent to the use of the photographs.

	Please place your initials in the box
I understand that the images of my chosen object will be held in accordance with the Data Protection Act	☐
Photographs can be studied by the researcher for use in the research project	☐
Photographs can be published in the researcher's PhD thesis	☐
Photographs can be published in any publications based on the research project	☐
Photographs can be used for educational purposes (to be viewed by students and professional)	☐
Photographs can be used in academic conference presentations and meetings	☐
Photographs can be posted to a website	☐

Photographs can be shown in the classrooms to students	☐
I understand that I have the right to refuse to take part in this study. I also have the right to withdraw from this part of the study at anytime before or even after the photographs are made.	☐
I also have the right to withdraw my permission for the uses of the photographs at any time, but I acknowledge that this cannot apply to uses of the photographs in work that has already been published.	☐
I have read and understood this consent form. I agree, or consent, to have the photograph of my chosen object taken as part of the study.	☐
I have been given a copy of this Consent Form.	☐

Your print name: _____

Your signature: _____ Date: _____

Signature of researcher: _____ Date: _____

Appendix XXII:

Dementia Consultation Group recommended study design changes

A teaching trust of Brighton and Sussex Medical School

Sussex Partnership NHS Foundation Trust

Dementia Consultation Group Meeting, Wednesday 6th April 2016

Sussex Education Centre, Seminar Room 2

10.30 – 12.30

Group members present: Jean Southey, Bryan and Christine Goodenough, Vickie Hale, Clare Ockwell, Thurstine Basset, Maureen Stansfield.

Meeting notes

Living Well with Dementia: sustaining psychological wellbeing in working family carers. Rachel Clarke

Rachel presented her research and opened up the discussion from the group's perspective:

- Had Rachel thought of finding out employers' attitudes to carer employees?
- Would the employers say what they actually meant?
- Would the carer be asked about other activities apart from work such as links with charities and local authorities which may not come under the heading of voluntary work?

Action: to add

Researchers clarified that there would be ethical issues getting consents for contacting employers. Their main interest was working family carers' perception of how they managed care and work. From this they would find out how flexible employers were.

The information sheet:

What are the possible disadvantages and risks of taking part?

- Issue - It is not true that there is *no risk* as it might open up the extent of a carer's depression for example. This could be a large risk.

Action: Need to change the statement.

- Could there be an addition on the lines that if the participant is affected during the course of the research further information on where to get help or support would be available?

Rachel will be doing a pilot study first. Whilst the questions cannot be reworded she can put effort into reading the language sensitively. She will stop and if necessary agree to visit a second time if the questionnaire is burdensome emotionally.

Will my taking part in the study be kept confidential?

- Before someone consents they may want to know more about what this sentence means. What is meant by "concerns for your mental or physical wellbeing" and who would the researcher be sharing the participant's details with. "So someone can talk to you about it (? Substitute - *these concerns)*"
- This could be clearer with a clarification of the researcher's responsibility.

Action to consider.

Stage 1

Length of time needed to complete questionnaire and ordering.

- This took one of the group nearly an hour to read through. It felt intensive and she felt weary by the end.
- Researchers often underestimate the time it takes to complete inventories with the researcher. It is important to have taken into account an initial warm up conversation first.

Action: Allow more time. This will give a better experience for the participant and researcher.

- At the pilot stage would it be useful to see what the best order for presenting the questionnaires is?

Questions.

- Question 9 and 16 - what is the value of these questions? They felt to be invasive.
- A1 "In most ways my life is close to ideal" This needs more gently working, it is huge if you are feeling frail.
- Is the question on climbing stairs necessary?

Action: clarity that there is a choice to answer or not. Reconsideration of how much information is needed for the purposes of the research. Is it overly comprehensive? Would it be possible for some questions not to be asked?

- Could an addition be made to the information sheet that explains the holistic nature of questions and the rationale for why they are being asked?
- It's important to avoid an implicit judgement from the questions.
- "At one point I felt as if I was being vetted for dementia, and I am one of your target group".
- Make it clear and help to frame what is positive and negative.
- Soften the wording – "Does this describe what you feel", put it in context.
- If possible in the design could you add your own questionnaire with strength statements. E.g. what do you get out of caring? So there is a section not on deficits but on strengths.

Action: to consider this, even if data for this section not analysed.

- The steps in the scaling on C – work and life balance do not work. For example from once a week to every day.

Design of Stage 1

- Could there be half the sample doing Stage 1 before 2 and half 2 before 1? This might mean that any negative effect impacting on the second meeting would be balanced out.

Researcher pointed out that it would not be good if Stage 1 was the final meeting, where the participant may be left in negative frame of mind.

Action to consider further.

- **(Added after the meeting on questions):** A58 and A65 are the same question. This question may be seen as intrusive and needs to be considered with care. Does it have to be asked?

Stage 2

- Choosing an object of personal significance. What was the experience of the group in imagining what they would choose?

- This was a struggle for one member who wondered whether there is a gender difference in the ease of undertaking this process. For example is there a gender difference in the choice based on feeling and thinking?
- Some participants may feel hopeless if they can't choose, may need encouragement with the process.
- Items referred to were, for example – photos, walking boots, meditation chair.
- The group were positive about this device within the research.

Other final points:

- Would the inclusion criteria include a specific age range? (*No)*
- Would the experience of carers who have other family dependents living at home be identified? *(To consider*).
- Dissemination: As widely to impact on local policy?

There would be a commitment locally and national to this overlooked group, especially as state retirement age is rising. It is hoped that the study has an impact on professional health and social care training.

Jenny and Rachel thanked the group and will get back to us with the design changes following on from this consultation.

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Appendix XXIII:

Modifications to the study design

Living Well with Dementia: Sustaining psychological wellbeing in working family carers

Study design changes following consultation on Wednesday 6th April 2016

The information sheet:

What are the possible disadvantages and risks of taking part?

- Issue - It is not true that there is *no risk* as it might open up the extent of a carer's depression for example. This could be a large risk.

Action: The statement in the information sheet has been changed to:

'There may be some risk of emotional distress by taking part in this study. If you feel uncomfortable during the interview, we can pause the session or completely stop.'

Could there be an addition on the lines that if the participant is affected during the course of the research further information on where to get help or support would be available?

Action: A pre-test of the study has been arranged for 31st May 2016. During fieldwork, questions will be read sensitively and stage 1 will be conducted in two visits, unless participants would prefer one visit. The researcher will also take care to read non-verbal cues which may signify discomfort and suggest respite where necessary. The information sheet reflects that sessions can be paused or stopped completely.

Will my taking part in the study be kept confidential?

- Before someone consents they may want to know more about what this sentence means. What is meant by "concerns for your mental or physical wellbeing" and who would the researcher be sharing the participant's details with. "So someone can talk to you about it (? Substitute - *these concerns)*"
- This could be clearer with a clarification of the researcher's responsibility.

Action: The information sheet now states:

If in the course of our discussions you expressed views that made me have *significant* concerns for your mental or physical wellbeing, only then do I have the responsibility in line with good research practice to inform a designated professional who would talk to you and offer appropriate support and protection.

Stage 1: Length of time needed to complete questionnaire and ordering.

- This took one of the group nearly an hour to read through. It felt intensive and she felt weary by the end.
- Researchers often underestimate the time it takes to complete inventories with the researcher. It is important to have taken into account an initial warm up conversation first.
- At the pilot stage would it be useful to see what the best order for presenting the questionnaires is?

Action: Two hours will be allowed for each visit and the information sheet now reflects this. We will review the ordering of questions during the pre-testing sessions.
Questions.

- Question 9 and 16 - what is the value of these questions? They felt to be invasive.
- A1 “In most ways my life is close to ideal” This needs more gently working, it is huge if you are feeling frail.
- Is the question on climbing stairs necessary?
- The steps in the scaling on C – work and life balance do not work. For example from once a week to every day.
- **(Added after the meeting on questions):** A58 and A65 are the same question. This question may be seen as intrusive and needs to be considered with care. Does it have to be asked?

Action: While all other questions discussed here were felt to be too valuable to be excluded from the study, we have removed the Life Satisfaction Scale (A1 – A5). The information sheet now advises participants that they can refuse to answer questions they would prefer not to.

Could an addition be made to the information sheet that explains the holistic nature of questions and the rationale for why they are being asked?

- It’s important to avoid an implicit judgement from the questions.
- “At one point I felt as if I was being vetted for dementia, and I am one of your target group”.
- Make it clear and help to frame what is positive and negative.
- Soften the wording – “Does this describe what you feel”, put it in context.
- If possible in the design could you add your own questionnaire with strength statements. E.g. what do you get out of caring? So there is a section not on deficits but on strengths.

Action: Questions will be softened and the holistic nature of questions will be explained beforehand. Questionnaires now include positive questions towards the caregiving role, including: the ‘Positive Aspects of Caregiving’ scale, and open-ended questions taken from the linked ‘Living Well with Dementia’ study.

- Choosing an object of personal significance. What was the experience of the group in imagining what they would choose?
- This was a struggle for one member who wondered whether there is a gender difference in the ease of undertaking this process. For example is there a gender difference in the choice based on feeling and thinking?
- Some participants may feel hopeless if they can’t choose, may need encouragement with the process.
- Items referred to were, for example – photos, walking boots, meditation chair.

- The group were positive about this device within the research.

Action: Participants will receive a verbal explanation following stage 1 and will be provided with an instruction sheet for stage 2, which assists with selection of an object of personal significance. The instruction sheet states that:

‘There are no restrictions to the type of object you select. For example, photographs and objects representing multiple areas which assist the work and life balance are acceptable, as long as one item is selected.’

Participants will also have two or three weeks between stage 1 and stage 2 to contact the researcher if they require further advice regarding the selection of an object.

Appendix XXIV:

Breakdown of age group for the full IDEAL cohort

		Frequency	Percent
	26	1	.1
	29	1	.1
	30	1	.1
	31	1	.1
	34	1	.1
	35	1	.1
	36	2	.2
	37	1	.1
	38	1	.1
	39	1	.1
	40	1	.1
	41	2	.2
	42	3	.2
	43	4	.3
	44	8	.6
	45	8	.6
	46	11	.9
	47	6	.5
	48	11	.9
	49	10	.8
	50	12	1.0
	51	11	.9
	52	17	1.4
	53	14	1.1
	54	12	1.0
	55	17	1.4
	56	17	1.4
	57	28	2.3
	58	11	.9
	59	22	1.8
	60	18	1.5
	61	24	1.9
	62	18	1.5
	63	35	2.8
	64	16	1.3
	65	28	2.3
	66	41	3.3
	67	45	3.6
	68	42	3.4
	69	41	3.3
	70	52	4.2
	71	52	4.2
	72	46	3.7
	73	56	4.5
	74	53	4.3

	75	40	3.2
	76	45	3.6
	77	51	4.1
	78	36	2.9
	79	46	3.7
	80	40	3.2
	81	26	2.1
	82	33	2.7
	83	27	2.2
	84	19	1.5
	85	20	1.6
	86	20	1.6
	87	9	.7
	88	8	.6
	89	5	.4
	90	2	.2
	91	1	.1
	92	3	.2
	96	1	.1
	99	1	.1
	Total	1236	99.8
Missing	System	2	.2
Total		1238	100.0

Appendix XXV:

Ethnicity and level of spoken English for the full IDEAL cohort

10. What is your ethnic group?			
		Frequency	Percent
Valid	White: English/Welsh/Scottish/Northern Irish/British	1228	95.7
	White: Irish	7	.5
	White: Gypsy or Irish Traveller	2	.2
	Any other White background; please specify	25	1.9
	Mixed White & Black: Caribbean	1	.1
	Mixed White & Black: African	1	.1
	Mixed White & Asian	1	.1
	Any other Mixed/multiple ethnic background; please specify	1	.1
	Asian/Asian British: Indian	2	.2
	Asian/Asian British: Pakistani	2	.2
	Any other Asian background; please specify	3	.2
	Black/Black British: Caribbean	2	.2
	Any other ethnic group; please specify	1	.1
	Total	1276	99.5
Missing	System	7	.5
	Total	1283	100.0

8. What is your main language?			
		Frequency	Percent
Valid	English	1258	98.1
	Welsh	7	.5
	Other; please specify	13	1.0
	Total	1278	99.6
Missing	System	5	.4
	Total	1283	100.0

9. How well can you speak English?			
		Frequency	Percent
Valid	Well	7	.5
	Very well	12	.9
	Total	19	1.5
Missing	System	1264	98.5
	Total	1283	100.0

Appendix XXVI:

Bivariate correlations (IDEAL instruments

		CESDR	Relative Stress Scale	Modified Social Restriction Scale	Rosenberg Self-Esteem Scale	Generalized Self-Efficacy Scale	COPE INDEX (Single item)	Management of Situation Scale	Positive Aspects of Caregiving Scale	Role Captivity Scale	Caregiving Competence Scale
CESDR	Pearson Correlation	1	.537**	.169**	.493**	-.284**	-.253**	.278**	-.169**	.347**	-.280**
	Sig. (2-tailed)		.000	.000	.000	.000	.000	.000	.000	.000	.000
	Sum of Squares and Cross-products	93792.885	51667.807	2362.390	22195.422	-12563.623	-1954.818	5760.739	-12816.547	8173.171	-4813.857
	Covariance	80.856	46.214	2.058	19.573	-11.040	-1.690	5.049	-11.174	7.119	-4.201
	N	1161	1119	1149	1135	1139	1158	1142	1148	1149	1147
Relative Stress Scale	Pearson Correlation	.537**	1	.328**	.395**	-.257**	-.409**	.501**	-.238**	.696**	-.425**
	Sig. (2-tailed)	.000		.000	.000	.000	.000	.000	.000	.000	.000
	Sum of Squares and Cross-products	51667.807	111861.976	4991.066	19559.767	-12309.135	-3463.134	11278.063	-19851.156	17817.848	-8077.463
	Covariance	46.214	96.683	4.340	17.340	-10.836	-3.006	9.824	-17.232	15.507	-6.981
	N	1119	1158	1151	1129	1137	1153	1149	1153	1150	1158
Modified Social Restriction Scale	Pearson Correlation	.169**	.328**	1	.147**	-.124**	-.168**	.090**	-.194**	.297**	-.172**
	Sig. (2-tailed)	.000	.000		.000	.000	.000	.002	.000	.000	.000
	Sum of Squares and Cross-products	2362.390	4991.066	2163.664	1036.083	-840.523	-200.681	285.036	-2269.704	1068.225	-457.756
	Covariance	2.058	4.340	1.817	.895	-.719	-.169	.242	-1.920	.903	-.386
	N	1149	1151	1192	1158	1170	1190	1180	1183	1184	1186
	Pearson Correlation	.493**	.395**	.147**	1	-.496**	-.275**	.124**	-.097**	.224**	-.342**

Rosenberg Self-Esteem Scale	Sig. (2-tailed)	.000	.000	.000		.000	.000	.000	.001	.000	.000
	Sum of Squares and Cross-products	22195.422	19559.767	1036.083	24085.997	-10979.115	-1075.720	1292.817	-3724.742	2650.584	-2967.685
	Covariance	19.573	17.340	.895	20.464	-9.481	-.923	1.119	-3.217	2.287	-2.556
	N	1135	1129	1158	1178	1159	1167	1156	1159	1160	1162
Generalized Self-Efficacy Scale	Pearson Correlation	-.284**	-.257**	-.124**	-.496**	1	.284**	.006	.136**	-.145**	.336**
	Sig. (2-tailed)	.000	.000	.000	.000		.000	.829	.000	.000	.000
	Sum of Squares and Cross-products	-12563.623	-12309.135	-840.523	-10979.115	21841.657	1068.297	62.991	4963.859	-1647.624	2804.611
	Covariance	-11.040	-10.836	-.719	-9.481	18.447	.908	.054	4.250	-1.408	2.395
	N	1139	1137	1170	1159	1185	1177	1166	1169	1171	1172
COPE INDEX (Single item)	Pearson Correlation	-.253**	-.409**	-.168**	-.275**	.284**	1	-.173**	.285**	-.312**	.685**
	Sig. (2-tailed)	.000	.000	.000	.000	.000		.000	.000	.000	.000
	Sum of Squares and Cross-products	-1954.818	-3463.134	-200.681	-1075.720	1068.297	667.597	-304.721	1837.654	-624.536	1013.750
	Covariance	-1.690	-3.006	-.169	-.923	.908	.556	-.258	1.551	-.525	.853
	N	1158	1153	1190	1167	1177	1201	1182	1186	1190	1189
Management of Situation Scale	Pearson Correlation	.278**	.501**	.090**	.124**	.006	-.173**	1	.039	.338**	-.181**
	Sig. (2-tailed)	.000	.000	.002	.000	.829	.000		.184	.000	.000
	Sum of Squares and Cross-products	5760.739	11278.063	285.036	1292.817	62.991	-304.721	4760.452	671.057	1797.065	-713.749
	Covariance	5.049	9.824	.242	1.119	.054	-.258	4.007	.568	1.528	-.604
	N	1142	1149	1180	1156	1166	1182	1189	1183	1177	1182
Positive Aspects of	Pearson Correlation	-.169**	-.238**	-.194**	-.097**	.136**	.285**	.039	1	-.313**	.289**
	Sig. (2-tailed)	.000	.000	.000	.001	.000	.000	.184		.000	.000

Caregiving Scale	Sum of Squares and Cross-products	-12816.547	-19851.156	-2269.704	-3724.742	4963.859	1837.654	671.057	64089.368	-6116.742	4199.570
	Covariance	-11.174	-17.232	-1.920	-3.217	4.250	1.551	.568	53.766	-5.188	3.547
	N	1148	1153	1183	1159	1169	1186	1183	1193	1180	1185
Role Captivity Scale	Pearson Correlation	.347**	.696**	.297**	.224**	-.145**	-.312**	.338**	-.313**	1	-.302**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000		.000
	Sum of Squares and Cross-products	8173.171	17817.848	1068.225	2650.584	-1647.624	-624.536	1797.065	-6116.742	6111.194	-1345.813
	Covariance	7.119	15.507	.903	2.287	-1.408	-.525	1.528	-5.188	5.131	-1.138
	N	1149	1150	1184	1160	1171	1190	1177	1180	1192	1184
Caregiving Competence Scale	Pearson Correlation	-.280**	-.425**	-.172**	-.342**	.336**	.685**	-.181**	.289**	-.302**	1
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000	.000	
	Sum of Squares and Cross-products	-4813.857	-8077.463	-457.756	-2967.685	2804.611	1013.750	-713.749	4199.570	-1345.813	3332.523
	Covariance	-4.201	-6.981	-.386	-2.556	2.395	.853	-.604	3.547	-1.138	2.786
	N	1147	1158	1186	1162	1172	1189	1182	1185	1184	1197
**. Correlation is significant at the 0.01 level (2-tailed).											

APPENDIX XXVII:

MANCOVA – Dementia working carers versus dementia non-working carers (revised sample)

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.419	263.331[b]	2.000	729.000	.000
	Wilks' Lambda	.581	263.331[b]	2.000	729.000	.000
	Hotelling's Trace	.722	263.331[b]	2.000	729.000	.000
	Roy's Largest Root	.722	263.331[b]	2.000	729.000	.000
Age	Pillai's Trace	.011	4.134[b]	2.000	729.000	.016
	Wilks' Lambda	.989	4.134[b]	2.000	729.000	.016
	Hotelling's Trace	.011	4.134[b]	2.000	729.000	.016
	Roy's Largest Root	.011	4.134[b]	2.000	729.000	.016
Dependence	Pillai's Trace	.056	21.433[b]	2.000	729.000	.000
	Wilks' Lambda	.944	21.433[b]	2.000	729.000	.000
	Hotelling's Trace	.059	21.433[b]	2.000	729.000	.000
	Roy's Largest Root	.059	21.433[b]	2.000	729.000	.000
Carer status	Pillai's Trace	.005	1.795[b]	2.000	729.000	.167
	Wilks' Lambda	.995	1.795[b]	2.000	729.000	.167
	Hotelling's Trace	.005	1.795[b]	2.000	729.000	.167
	Roy's Largest Root	.005	1.795[b]	2.000	729.000	.167
Gender	Pillai's Trace	.066	25.882[b]	2.000	729.000	.000
	Wilks' Lambda	.934	25.882[b]	2.000	729.000	.000
	Hotelling's Trace	.071	25.882[b]	2.000	729.000	.000
	Roy's Largest Root	.071	25.882[b]	2.000	729.000	.000
Working status	Pillai's Trace	.026	9.723[b]	2.000	729.000	.000
	Wilks' Lambda	.974	9.723[b]	2.000	729.000	.000
	Hotelling's Trace	.027	9.723[b]	2.000	729.000	.000
	Roy's Largest Root	.027	9.723[b]	2.000	729.000	.000